

by

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# **Chronic Illness Trauma Studies**

read the Essential Guide blog post

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Having had a chronic illness for 20 years, it has sometimes felt like I've had a volcano inside of me - out of my control, traumatic, and completely life-altering.

But research explaining links between chronic illness, trauma and the nervous system has made sense of my illness and helped me realize that my symptoms aren't what I learned to believe in my medical training.

It has also provided insights that have been helping me, clients I've worked with, and others I've gotten to know and read, begin to heal in slow, gentle, informed ways.

Here's what you need to know if you or a loved one has a chronic illness.

You can use this post as a reference page for Chronic Illness Trauma Studies. The sections link to blog posts with more detail and references to help you find your way.

# **Essential Guide**

TO CHRONIC ILLNESS, TRAUMA AND THE NERVOUS SYSTEM





This post also introduces my logo, with chronic illness and other health conditions represented by the volcano and all the healing that is possible reflected by the green triangle that surrounds and quells the volcano, and the sun, which is an example of the power of safety, resources and support.

The graphics in this post will explain more.

# I. Chapter 1: Why Chronic Illness Feels Like A Volcano



- Chronic illness is like a volcano inescapable, often terrifying, overwhelming and potentially life-threatening. Like other natural disasters, these are also common experiences of trauma.
- Like a volcano, chronic illness can take away your home, your livelihood, your relationships and your financial stability. It can rob you of your confidence and your sense of safety in the world. These, too, are inherent in experiences of trauma.
- Like chronic illness, the transformation of solid rock into lava is invisible to the outside observer even as it profoundly changes our inner core.

There is, however, an underlying intelligence to both volcanoes and chronic illness:

- It allows pressure that has been building to release from deep within.
- The heat that grows inside and erupts as symptoms is old and unresolved, looking for a way out.
- And this offers us clues.

We've long been taught we could only watch this process of disease and that it was out of our control - but science is discovering that unresolved trauma, like lava, can emerge in much gentler, safer ways or in different ways altogether. And that pathways are available even after eruptions or symptoms have begun.

When a volcano erupts inside our bodies and wreaks havoc in our lives, it also provides an opportunity to look at ourselves in new ways. To find what is most valuable, and reclaim it. To look at what has been too scary, intimidating, or for which we haven't had the time. To cut into the abscess we thought we could ignore, or didn't realize we had, and allow it to begin to actually heal.

- Healing happens over time, and in slightly different ways for everyone.
- Like dealing with a volcano, it takes courage but with the right tools, it is doable. It's been happening with my own health and I've seen it and heard about it with others too.
- Healing starts with understanding the role of life experiences and how they shape our long-term health.
  - Like a volcano, it's not psychological.
  - Like a volcano, it's very real.
- Next, understanding where lava comes from and why it flows helps us recognize early warning signs. This enables us to take inventory and identify what needs to be done. The same is true in illness.
  - Understanding helps us recognize triggers and find tools that will helps us work with, decrease and begin to prevent symptoms and flares.
- We then begin to see that symptoms don't arise overnight.
- Like volcanoes, chronic illnesses develop gradually, over years and often over decades.
- Because our brains and nervous systems, immune systems, guts and bodies are still being shaped and influenced by our environments in the present moment, even in adulthood, we can modify the course of the eruptions, identify gentle approaches that fit our own unique needs, and gradually begin to quell what we once thought was out of our control.

**The trauma perspective has changed my life so enormously for the better.** My symptoms of chronic fatigue, which very likely has an autoimmune component along with the nervous system disruptions, has been gradually improving instead of steadily worsening, as it did for the first 10 years of my illness. The process of healing has been very gradual, but it has made sense of so much and helped me find more joy in my life as well as improving health.

Here's an overview of the science, how to make sense of symptoms, and examples of tools that will help.

## Mini Survey: Reader Health

Link to the survey in the <u>blog post</u> table of contents at the top of the page

#### Learn more:

How Understanding Trauma is Making Sense of My Chronic Fatigue (ME/CFS) and Helping Me Heal

# **Risk for Chronic Illness Begins Long Before Onset**



- The destructive process leading to autoimmune diseases such as type 1 diabetes, rheumatoid arthritis, lupus and others begins years and often decades before symptoms ever arise.
- <u>Dr. Charles Poser</u>, a researcher in multiple sclerosis (MS), compared this invisible phase of disease development to the arising of <u>an undersea volcano</u>.
- Like a volcano growing slowly beneath the surface of the ocean, physiological changes associated with disease processes begins in small ways that don't at first cause symptoms.
- The process of disease development only develops into a disease over time, in some individuals, some of the time.
- For example,
  - plaque is observable in arteries and signifies risk for heart attacks. It can be present long before symptoms occur. Plaque is reversible, however, and not everyone with plaque has a heart attack or ever develops recognizable physical symptoms of heart disease.
  - autopsies show evidence of decreased myelination consistent with MS,
    Alzheimer's or Parkinson's in some people who never developed symptoms of

these diseases. These are other examples of the undersea volcano that can brew without ever breaching the surface or becoming visible or problematic.

• Symptoms of chronic illness only begin after a certain threshold of the disease process has been crossed and if we experience too many adversities in the face of too little support.

I had brief symptoms of intense fatigue once in childhood during a hike and once on a multi-day bicycle tour after college, when I was unusually exhausted even after calling it a day by early afternoon and resting until the next morning. Many people with chronic illness also remember having brief periods of symptoms years and decades before the onset of their diseases. These are small clues that reflect a developing change in physiology that may never progress into an actual disease and that may instead resolve entirely. Just as a chronic illness may decrease or resolve with treatment later in life.

#### Learn more:

<u>#1 Early Trauma and Autoimmune Disease: Clues from Antibodies, Genes & Type 1 Diabetes</u>

# It's Nature AND Nurture, Not Either / Or

## **Risk for Chronic Illness** 70-90% Risk Comes from Environment toxins chemicals Genes 10-30% diet inflammation trauma 70-90% risk comes from Environmental stress Exposures infections Rappaport, Stanford in Science, 2010 Veronique Mead, MD, MA Chronic Illness Trauma Studies.com

- It has long been believed that every chronic illness has a different cause.
- It has also been thought that there are physical causes for physical diseases, and mental and emotional causes for mental illness.
- The science finds that mind, body and spirit interact with one another, however, just as ancient world traditions have known since the beginning of time.
- While genes can predispose us to risk for certain chronic illnesses, science is discovering that most of the time exposure to life experiences and other elements in our environments are necessary for symptoms to develop. This is how nature (genes and physiology) interacts with nurture (early relationships and other life experiences) to shape long-term health.
- Environmental factors which include diet, stress, infections, toxins and trauma, among others are responsible for <u>up to 70-90% of risk</u> for chronic illness ((Rappaport, S. M. (2016). "Genetic Factors Are Not the Major Causes of Chronic Diseases." PloS One 11(4): e0154387 see more in <u>Rappaport & Smith</u>).
- We can no longer separate mind from body and think they operate independently from our life experiences and our earliest relationships.

Illness has forced me to recognize that I have feelings, emotions and healthy impulses that cannot be ignored, shoved aside, or otherwise negated any longer if I want to heal.

When changing my diet, slowing down and leaving my career to decrease stress and listen to my soul's desire for deeper meaning didn't cure me, I dug more deeply in search of answers about chronic illness.

That's when I started learning that I couldn't fully move forward into my life, into joy and relationship, and into my gifts unless I addressed the unresolved protections I'd built from past vulnerabilities and overwhelm.

The same appears to be true for most of us struggling with physical and emotional symptoms, dissatisfaction with work life, a loss of meaning, and much more.



- Interactions between genes and our environments shape how active our genes become, which ones are turned on or off, and which ones function somewhere in between.
- Life experiences and other environmental exposures affect gene regulation by attaching small chemicals to genes. This happens through epigenetics.

#### Learn more:

Epigenetics and Chronic Illness: Why Symptoms May Be Reversible

# II. Chapter 2: Gene-Environment Interactions Shape Health



# Genes

- Genes produce proteins, enzymes, and building blocks that create our bodies, tissues, antibodies and much more. Products our genes create affect metabolism, digestion and the many ways our physiology functions all day long.
- Genes, however, do not operate on their own or in a vacuum.
- Gene function, activity and inactivity is influenced on a daily basis by adverse and supportive life experiences, diet and exercise and other environmental factors.
- The environment shapes gene function through the attachment of tiny chemicals to the surface of our DNA in the evolving new science of epigenetics.
- In contrast with genes, which we cannot change, epigenetics can be altered and reversed. This happens through diet, exercise, trauma therapies and more. This is part of why understanding environmental factors and taking action for our health can support healing and recovery.

# Telomeres

- Telomeres are areas at the end of chromosomes that protect our genes from destruction.
- Shorter telomeres link to shorter life spans.
- Shorter telomeres change the function of cells and induce early cell death and even programmed self-destruction (apoptosis).
- Telomeres naturally shorten over our lifetimes but can be shortened more rapidly through environmental exposures to stress, trauma and other factors.

I have multiple relatives on both sides of my family who have had debilitating chronic fatigue severe enough that they've been unable to work. And I come from a family of workaholics (who knows, that might be related to our illnesses too!).

While this degree of family illness suggests a possible genetic component that I've inherited, it also reflect shared histories and life experiences. And the fact that I've been healing - even as it has taken time - supports the growing understanding that we have tools that can help us exert profound and long-lasting positive effects on our health even when we carry underlying genetic risk.

## Learn more:

Mechanisms of How Trauma Shapes Risk for Chronic Illness

# The Nervous System and Health

# <complex-block>

- The nervous system and other organ systems begin development in the womb soon after conception.
- Growth continues during birth, in childhood and our teenage years, and beyond.
- Many more neurons and cells than will ever be needed are created very early in development in the womb and in childhood.
- Neurons and pathways that are used are strengthened and maintained.
- Such neurons and pathways are often also myelinated over time, which increases the speed and stability of the signals.
- Connections between neurons are affected by practice, life experiences and other nongenetic factors:
  - Exercise increases aerobic and muscle capacity for example, and practicing the piano increases our skill levels. This occurs through strengthening of networks in high use.
  - In contrast, lack of practice leads to atrophy, weaker muscle groups and loss of skills. This occurs through pruning and removal of unused connections.
- This capacity of the brain and nervous system to change with experience is known as brain plasticity.
- Links between chronic illness, trauma and the nervous system are what enable us to recover and heal, to much greater extents than has been recognized or thought possible.

**Changes I've made to my diet, with stress reduction, sleep hygiene, exercise and especially in healing trauma are all helping me to heal.** Each tool you use plants seeds that support healing. You can learn which tools feel the most helpful to you and your specific nervous system patterns, which ones you enjoy the most, and which ones you are the most willing to persevere with. Over time you'll notice how these seeds sprout to support improvements in your health.



- Our nervous systems are designed to rest, digest and handle routine activity. They are also organized to cope with adversity, stress and trauma.
- This is because our bodies have an innate drive for health as well as the capacity for recovery.
- Health is optimized through autonomic nervous system (ANS) function.
- The polyvagal theory, originally formulated by physiologist Stephen Porges, Ph.D. explains that the ANS is composed of three branches rather than the two we learn about in school.
- The sympathetic nervous system branch of the ANS supports our body's ability to move, act and exercise. It also facilitates our survival states of fight and flight.
- The parasympathetic nervous system is composed of two branches rather than one.
- *The dorsal vagal branch* of the parasympathetic becomes functional early in the womb. It supports rest, digestion and recuperation. It is also responsible for the freeze response, which supports survival by helping us become very still and therefore relatively invisible to predators.

- Freezing is an important option for babies in and outside of the womb because they cannot protect themselves by running or fighting in the event of danger or threat.
- Slowing down, immobilizing and waiting until a threat passes are survival strategies used when we are relatively helpless and when fight/flight are either not available or not viable options.
- *The social nervous system* is the other branch of the parasympathetic nervous system.
  - It is what enables babies and parents to bond at birth.
  - It helps humans and other animals to form relationships with others throughout life.
  - This branch supports the most energy-efficient form of survival and protection we have that of communication and connection.
  - When babies bond to their parents, the simple act of crying in hunger, reaching up to be held, or curling into adult bodies for safety, comfort and sleep are energy efficient ways of getting the life-giving support necessary for survival.

These perspectives enabled you to recognize what is happening in you nervous system on a daily basis and make sense of how you feel. For example, it can explain big dips in energy levels, rapid spikes in anxiety over little things that aren't that important or threatening, startle responses that can send your heart pounding, difficulty slowing down and resting as well as sleeping, and times of feeling wired and tired at the same time. These are indications that your nervous system is operating outside of optimal function. In other words, they suggest that your social nervous system is not fully available to calm these excessive responses down or prevent them. All of these responses can improve with time.

And you can learn to recognize them and not let them stress you further once you have a context.

# **III.** Chapter 3: Life Experiences Influence Health

# Adverse Life Events Increase Risk for Chronic Illness



- Adverse life events and trauma are important environmental risk factors for chronic physical illness, mental illness, chronic pain and other health conditions. They are also risk factors for addictions to work, food, alcohol and other substances, and to other distractions.
- Chronic illness does not arise from a single event but from an accumulation of adverse life experiences and unresolved trauma.
- The effects of adverse experiences begin before conception, occur in the womb and at birth, and continue throughout our lives.
- Risk can arise from many "little" traumas or from a smaller number of "big" traumas.
- Trauma and adverse events alter the nervous system, epigenetics, telomeres and more.

I never thought I had experienced trauma even though I had certainly lived through adversity, like most people. But even with that concession, I didn't think of my car accidents as having been that bad since I had walked away from all of them. And I didn't dwell on some of the other, more scary things I'd been through. Like most people, I was completely unable to recognize that such events might affect me, let alone influence my health.

# Supportive Life Events Decrease Risk for Chronic Illness



- We all experience trauma simply by being human it can occur during an arduous birth, in childhood, and throughout our lives.
- Our nervous systems are designed to recover from trauma when we have enough resources, support and time.
- When we have highly available supportive, safe, nurturing connections such as with parents or other caregivers it helps us cope and recover more quickly and fully from experiences of adversity and trauma.
- Having enough time to prepare for a difficult experience such as a natural disaster, or to integrate and heal from what happened (such as the loss of a loved one) is another key resource that supports our body's innate capacity to recover.
- Health is maximized when we encounter life's inevitable challenges and traumas in the context of support and resource. This is how resiliency develops.
- Having even one adult who listens, sees you and comforts you in some way, can make all the difference in supporting greater health even in the face of abuse and other adversity. This person may be a parent or grandparent, a teacher or neighbour.
- The power and positive effects of supportive, resourcing others and environments are known as "Buffers" because of how they can lessen, mitigate, moderate the effects of trauma and other life challenges.

I grew up in an upper middle class family with plenty to eat, support for hobbies, a good school, and in safe neighbourhoods. In addition to my parents, I had relatives who loved me

and we had big, fun, regular family gatherings. What I never realized was that I also felt incredibly alone as a child in spite of it all. What my symptoms, triggers and the research gradually taught me was how subtle the imbalances can be that influence our bodies and nervous systems. Feeling alone without even being quite conscious of this was one of the clues that I eventually was able to understand. Trauma and adversity can have an impact on our nervous systems even when we are privileged, have two healthy parents, and seem to have no worries in our lives.

# What is Trauma?



# Neurologist Robert Scaer, MD

# What is Trauma?

"This [DSM] definition [of trauma] isn't wrong, but it's woefully incomplete... Any negative life event occurring in a state of relative helplessness--a car accident, the sudden death of a loved one, a frightening medical procedure, a significant experience of rejection--can produce the same neurophysiological changes in the brain as do combat, rape, or abuse. What makes a negative life event traumatizing isn't the lifethreatening nature of the event, but rather the degree of helplessness it engenders and one's history of prior trauma."

from

# Three Ways Mindfulness Can Heal After Trauma

Veronique Mead, MD, MA Chronic Illness Trauma Studies.com

Caption: Quote from neurologist Dr. Robert Scaer, author of The Trauma Spectrum: Hidden wounds and human resiliency (2005), from <u>Three Ways Mindfulness Can Heal Trauma</u>.

- Trauma is an experience that interrupts life, health and flow.
- It is an experience that either overtly or at some subtle level we cannot cope with, escape or surmount. As a result, trauma is an experience of relative helplessness and overwhelm.
- The effect of trauma is to hold our nervous systems in the past, trying to survive an event that we haven't ever successfully escaped.

- The changes in the nervous system that occur from trauma persist, even after events are long gone.
- Trauma is therefore a state that holds our nervous systems hostage in the past.
- While experiences such as war, rape, or natural disasters are commonly traumatic for most people, much subtler and smaller events can be just as traumatizing.
- Trauma is about *how* we experience an event rather than a specific kind of event itself.
- Trauma is also about events we do NOT experience but that our bodies and nervous systems need for healthy growth and development. I'll share more in the 6 types of trauma below.
- Trauma can arise from an experience that
  - is life-threatening (a car accident)
  - seems life-threatening (bankruptcy, chronic illness, narrowly avoiding hitting a pedestrian)
  - where too much happens too fast (think bike accident, surgery or a fall),
  - feels overwhelming (loss of a parent in childhood for any reason, including divorce; loss of a job or spouse; witnessing violence)
  - o feels inescapable (premature birth, chemotherapy, a natural disaster), or
  - feels hopeless (failing a critical exam, abuse, war)
- Trauma can occur when we have identifiable way to escape a challenging or scary situation (getting lost, sexual harassment, being diagnosed with a life-threatening disease).
- The effects of trauma occur when neither talking and communicating, nor fight and flight are effective or available options. This is when we feel some degree of helplessness, which triggers a freeze response.
- Symptoms arise when our only recourse has been to immobilize, hunker down, or give up.
- Being in a situation where the defense strategy of freeze/immobility is evoked is what leads to symptoms of trauma.

As I gradually learned the many different forms that trauma can take, I started to wonder about some of my life experiences and whether they had caused feelings of overwhelm, helplessness or freeze that had been too subtle to notice. As an adult, for example, I was assaulted at home in the middle of the night; experienced 3 car accidents, including a roll over; and underwent surgery with general anesthesia to remove a cancerous tumor. These were just a few of the events that I began to wonder about and realize could have influenced my health.

#### Learn more:

My Story: How Understanding Trauma is Making Sense of My Chronic Fatigue (ME/CFS) and Helping Me Heal

What are symptoms of trauma?

How to recognize if you have symptoms of trauma (free ebook #2)

Trauma May be an Important Cause of Type 1 Diabetes: Dan's Story and Symptoms

# The Old Understanding of Chronic Illness & Trauma is False

# The Old Model is False



The old view says trauma causes psychological symptoms therefore a history of trauma means chronic illness is psychological too. New research shows this view is false and out of date.



- The belief that trauma and adverse life events causes psychological symptoms such as PTSD (post traumatic stress disorder), anxiety, nightmares and other mental health conditions is true.
- The belief that psychological symptoms are the ONLY effects of trauma, however, is false.
- The perspective that a chronic illness is "all in our heads," psychological, or implies laziness and attention-seeking is out of date and inaccurate.
- This outmoded belief is just as false for chronic illnesses that have clear diagnostic tests to prove their existence (type 1 diabetes, for example) as it is for those for which no objective, measurable test exists to document symptoms (chronic fatigue, irritable bowel syndrome).
- The difference between "functional" diseases that have no visible abnormalities and those for which objective findings exist is a matter of timing of exposure to early trauma rather than a difference between "real" or "less real" disease (see below under 6 Types of Trauma #1. Trauma in the Womb, Birth & Infancy).
- These old views judgmental, shaming, and blaming have lead vast numbers of people with debilitating, life-altering chronic illnesses to doubt the validity of their symptoms and they no longer hold water.
- Science shows us a new way of making sense of chronic diseases, who is at risk, and what we can do about it.

Every week I read another story of someone with a chronic illness who has been shunned, doubted or blamed for faking their illness, overdramatizing their symptoms, or "just needing

to relax" despite being too incapacitated to take care of their children, pursue a long-standing professional hobby or perform work they love. Even when they have subtle signs of illness that are recognizable when doctors know what to look for - and especially when none of their symptoms can be objectively measured. It breaks my heart. It also enrages and scares me. My fear of this happening was one of the reasons I avoided doctors for the first 10 years of my illness - even though I was a doctor myself.

#### Learn more:

<u>Why Chronic Illness is Not Psychological (Even if You Have a History of Trauma)</u> (free ebook #3)

Stress, Trauma and Type 1 Diabetes (Why Doctors Don't Know the Research)

Mind Body Medicine and Chronic Illness (It's Not All in Your Head)

Video Intro to Chronic Illness, Trauma, & Why It's Not Psychological

# IV. Chapter 4: Chronic Illness, Trauma & The Nervous System

# Science Introduces a New Understanding of Chronic Disease



Chronic illness is one effect of trauma. Trauma alters nervous system & gene function to influence health. The cause is not psychological.



- Decades of research are beginning to change how we understand the role of life experiences in shaping gene activation, nervous system function and consequently health.
- The science comes from many different disciplines epidemiology, epigenetics, child development, embryology, prenatal and perinatal medicine, neurophysiology, traumatic stress, patterns of apoptosis and cell function, sensitive periods of organ maturation, brain maturation, and much more, including studies in individual diseases.

It took a few years of avidly watching my symptoms before I saw my first links to trauma from my past. I started to realize that conflict or reading about birth trauma could trigger a worsening of my fatigue. And even though my baseline fatigue didn't change, when I recognized some of these triggers or worked to resolve the events they linked to, my fatigue flares eased up.

The extent of the connections to symptom flares and past adversities continues to awe me with its subtleties and the degree to which I see its effects in my everyday life.

The links between chronic illness, trauma and the nervous system continue to emerge as I pay attention, persevere with trauma therapies, and chip away at old, deeply embedded patterns within my nervous system.

#### Learn more:

How Trauma Affects Risk For Chronic Illness: Summary of the Science (+ 11 Characteristics that Can Make Sense of Symptoms)

# Trauma Increases Risk for Chronic Illness



- When we experience adverse life events and / or trauma in the face of insufficiently supportive, nurturing environments, risk for autoimmune diseases and chronic illness increases.
- Trauma alters gene function through epigenetics.
- Adversity and stress shorten telomeres and decrease longevity.
- Difficult life experiences shift the way our nervous systems function.
- The science shows that life experiences imbed themselves in our biology and explains the powerful links between chronic illness, trauma and the nervous system.

## Learn more:

#3 Early Trauma and Epigenetics Make Sense of Chronic Disease (and Healing)

# Trauma Alters the Nervous System

# Trauma Interrupts Health The Nervous System Loses Balance



- The social nervous system is designed to regulate as well as inhibit survival states of fight, flight and freeze when they are not necessary.
- Trauma disrupts our social nervous system's ability to inhibit and regulate the other branches of the ANS.
- Trauma disrupts our boundaries, our ability to feel safe, and our capacity for connection to others. These are all functions of the social nervous system.
- In unresolved trauma, our nervous systems are caught in self-perpetuating states of fight, flight or freeze (or combinations of these). This is because when we don't recover from trauma our brain's perceive we are still in the event, struggling for survival, caught in the past.
- Because trauma alters our nervous systems and gene function, it also changes our physiology, emotions, behaviors and thoughts.
- The intelligence that underlies unresolved trauma and its effects is that our nervous systems are looking for a way to succeed at overcoming what it couldn't in the past.
- When our brains receive the message that we have successfully escaped a life-threatening or otherwise overwhelming event, it turns off the survival response and returns our nervous systems to healthy baselines.
- Healing and resolving trauma also reengages our social nervous systems so our physiologies, tissues and cells can return to states of restorative calm and health.
- In unresolved trauma, our brains actively maintain our physiologies and cellular functions and more in states of fight, flight and/or freeze. These are attempts to preserve our lives

and ensure survival, even if the cost involves attacking parts of our tissues to maintain these states. This intelligent support is what I believe occurs in autoimmune illness, rather than random attacks on the self by bodies that are making mistakes, as is currently believed.

- Having a history of trauma does not mean that a chronic illness is psychological or all in our heads. Chronic illness is simply another effect of trauma, as are changes in mental health, emotions, behaviors and thoughts.
- Trauma affects our bodies, nervous systems and emotions by regulating genes through epigenetics, guiding our sensitivity to stress, and other functions.

I grew up with underlying feelings of depression even though it was not diagnosed until half way through my first year of internship, when I started crying almost every day. I had thought of suicide on and off during my college years and in medical school, craving escape from the deeply painful feelings. I had never discussed it in depth or been in therapy, however, as it had seemed a fact of life and I had assumed it was just part of who I was. I see in retrospect that this was one of the early signs of trauma that eventually worsened in the direction of chronic fatigue. This isn't because my ME/CFS is psychological, but because both depression and unrelenting fatigue reflect a nervous system caught in a state of dorsal vagal freeze. One was an early symptom, the later one a deeper, physiological, metabolic symptom.

# Chronic Illness is a Nervous System Issue Trauma Alters Physiology



- When we carry unresolved trauma, our nervous systems are caught in the past.
- With unresolved trauma, our brains misinterpret the present moment and maintain hypervigilance or freeze (or both).
- With unresolved trauma our ANS has difficulty taking effective, satisfying action. It also has problems resting. It may maintain states of fight /flight, which can look like speeding up and staying very busy or being anxious and jumpy; and freeze, which can make it hard to make decisions, schedule appointments, spend time with friends, or feel energy. Or we may experience various combinations of these states.
- Research in chronic illness, trauma and the nervous system explains how this happens.

In the early days when my fatigue first started I used my basic knowledge as a doctor to test my blood sugar, iron and B12 levels, thyroid function, HIV status in case I'd exposed myself, white blood cells for indications of infection, along with other basics to make sure I didn't have any common causes of fatigue. What I didn't know then was that my very low cholesterol levels (140) and history of low blood pressure (running in the 90-100/60) were both clues to a nervous system that might be in the early phases of a freeze response (which lowers most functions towards the death-like state of immobility).

## **Trauma Increases Sensitivity To Risk Factors for Chronic Illness Increases Sensitivity to** toxins Alters chemicals **Nervous System** Trauma diet Responses to inflammation Threat stress infections Veronique Mead, MD, MA Chronic illness Trauma Studies.com

- Chronic illnesses often begin after a period of emotional or physical stress, trauma, exposure to a toxin such as mold, or to other threat, such as an infection.
- Trauma makes our nervous systems and immune systems more sensitive to threat.
- Trauma also interferes with our nervous system's ability to perceive threat accurately in the present moment. It makes our systems more sensitive to threat, more likely to misinterpret our environments as threatening when all is fine, and leads to reactions that are unnecessary or larger than necessary.
- Some toxins directly affect our nervous systems and other organ systems, especially during times of early development in the womb, infancy and in childhood.
  - Thalidomide is an example of a chemical that changes the healthy development of the physical body and physiology when organ systems were growing in specific ways. Its effects are the result of direct toxicity
- Life experiences and trauma act in more subtle ways to influence the direction our ANS and physiology take such as towards higher or lesser sensitivity to stress as a survival mechanism, which sets different baseline levels of metabolism, cell function, blood pressure, heart rhythms, insulin regulation and much more.
- Trauma and changes it exerts on epigenetics, telomeres and the nervous system, among others may be the common denominator that increases sensitivity to environmental risk factors for chronic illnesses of all kinds.

Over the 20 years I have been sick with chronic fatigue (ME/CFS), I have also developed increasing sensitivities to foods and problems with gut function (which fits the label of irritable bowel syndrome or IBS). These food sensitivities have worsened despite ongoing trauma work. As a result of working with past adversity and learning to listen to my body,

however, I have noticed that I stuff anger, rage and other difficult feelings down into my belly. There was nowhere else to put them when I was a child and my parents didn't know what to do with difficult emotions. I have come to see that these symptoms, like my altered metabolic functions and energy levels, are clues that reflect a digestive system still caught in a state of relative freeze and increased perceptions of threat. As such, I'm not allergic to these foods and do not have a "broken gut," but live in a body that still thinks immobilizing digestion as well as availability of fuel and energy is what it needs to do to help me survive.



- Symptoms of chronic illness reflect long-standing survival states of fight, flight and freeze that are maintained and perpetuated by our nervous systems.
- These long-standing survival states evolve, increase and decrease over time based on continued life experiences.
- Trauma can resolve on its own when we've had enough time or support, or through help such as trauma therapy. When unresolved trauma does not heal, however, nervous system patterns intensify over time and eventually emerge as a chronic illness or other effect of trauma.
- Chronic illness is therefore a nervous system issue first, and only becomes a tissue issue imbalances in hormones, enzymes, myelin, gut flora and other biological tissues and cell functions - over time. I've adapted this perspective from neurologist Dr. Robert Scaer's view about trauma, which originally states that "trauma is a nervous system issue, not a tissue issue."
- The research suggests our current medical view that chronic illness occurs in bodies that are randomly broken or accidentally self-destructing through antibodies is inaccurate.
- The link between chronic illness, trauma and the nervous system is an intelligent one, albeit one that no longer serves the best interests of our health, lives, and function.

## Learn more:

<u>#1 Early Trauma and Autoimmune Disease: Clues from Antibodies, Genes & Type 1 Diabetes</u>

# Trauma Increases Risk for Chronic Illness

# Trauma Increases Risk for Autoimmune & Other Chronic Illnesses



Addison's Asthma Autoimmune Disease Cancer Celiac disease Chronic Fatigue (ME/CFS) Coronary heart disease Diabetes, type 1 Diabetes, type 2 Fibromyalgia (FMS) Grave's (Thyroid) Hashimoto's (Thyroid) Headaches **High Cholesterol** Hypertension Insulin Resistance

Irritable Bowel Syndrome Inflammatory Bowel Disease Liver Disease Lupus Metabolic Syndrome Multiple Sclerosis Myasthenia Gravis Obesity Pain Psoriasis Rheumatoid arthritis Sjogren's **Sleep Disorders** Stroke Thrombocytopenia Purpura & more ....

- Research studies find trauma to be a risk factor for autoimmune diseases of all kinds. These include:
  - o MS
  - rheumatoid arthritis
  - type 1 diabetes
  - o lupus,
  - $\circ$  and others
- Studies show that trauma is also a risk factor for many other chronic illnesses, such as
  - heart disease
  - insulin resistance
  - o obesity
  - o type 2 diabetes
  - high blood pressure
  - high cholesterol
  - metabolic syndrome
  - headaches and other types of chronic pain
  - o psoriasis
  - chronic fatigue
  - $_{\odot}$  fibromyalgia

- o asthma
- sleep disorders
- o strokes
- $_{\odot}$  thyroid disease and beyond

#### Learn more:

The Chronic Illness and Trauma Series: 30+ Diseases Increased by Adversity

Trauma research in type 1 diabetes

Trauma and healing in *rheumatoid arthritis* 

Trauma research and curing asthma

Working with my symptoms of IBS (irritable bowel syndrome)

Posts about the onset of my chronic fatigue (ME/CFS), first steps & early insights

# V. Chapter 5: The Balance Between Trauma & Support Shapes Risk for Chronic Illness Long Before Onset

The research supports at least 6 broad categories of trauma that are known to affect risk for chronic illness.



When I was a doctor I never knew about research showing that trauma is associated with increased risk for chronic illness, even though some studies had been conducted decades before I went to medical school.

As a family doctor, the only understanding of trauma I was given was the physical trauma doctors can address that occur to our bodies from accidents, surgery, and acts of violence. Doctors still think this way today and if the concept of trauma arises, it is still thought to be relevant only to mental health.

Research about the 6 types of trauma below emphasize that medical training and care need to be brought up to speed.

As my health continues to improve, I fantasize about being able to go back to work one day. And one of my dreams is to teach medical students and residents about this research.

Because getting a clear understanding of the full effects of trauma and adversity will revolutionize medicine and the outlook for anyone diagnosed with a chronic illness.

# **#1** Trauma in the Womb, Birth & the First 2 Years of Life: Adverse Babyhood Experiences (ABEs)



**Rachel Naomi Remen is a pediatrician who** developed inflammatory bowel disease (IBD) when she was 15 years old and was not expected to live beyond her 40s, given the severity of this disease and the limitations of treatment at the time. The following excerpt is from her book "Kitchen Table Wisdom."

I too had come early. My mother had suffered from toxemia and I had been delivered by emergency cesarean section far below full-term weight. In 1938, I had not been expected to live. All throughout my childhood I had been told I had survived because of the invention of the incubator ... Now as a young pediatrician I was working in a premature intensive-care nursery far more powerful technology to keep other babies alive. [I began to wonder,] perhaps survival was not only a question of the skillful use of state-of-the-art technology, perhaps there was something innate, some strength in those tiny pink infants, that enabled both them and me to survive ...

Being exposed to illness in the womb or during infancy, to a difficult or early birth, or to maternal grief or stress are common in human life. All are repairable. They are, however, risk factors for chronic illness.

Risk occurs in a variety of ways, including through

- disruptions in babies' developing nervous systems and other organ systems
- interruptions to bonding, which helps a baby's immature nervous system develop
- decreases in parents' abilities to attune to their babies,
- timing of exposure during critical windows of time when environmental factors shape growing organ and systems

Events such as being born prematurely, by forceps, needing oxygen or other resuscitation at birth, needing hospitalization or incubator care, not being breastfed, and more are all risk factors for disease.

- Risk appears to be low, however, unless additional trauma occurs in childhood in conjunction with insufficient support and resource.
- While early experiences can have very powerful effects in shaping health, we are designed to heal and recover from even these types of interruptions and events.
- The key message to remember is that it's never too late to begin to heal.
- Take the mini survey to get a sense of how many of us have experienced trauma or adversity in the period leading up to conception, during pregnancy, labor and birth, and through our first 2 years of life. For ease, I refer to this period as "babyhood."



# **Co-Regulation is Needed for Development**

- The Dutch Hunger Winter is one of the earliest and longest still-ongoing studies evaluating the effects of stress and trauma before birth. It shows that early adversity, such as happened to this Dutch population held under siege during World War II, increases risk for chronic illness for at least the following two generations: in children and grandchildren.
- At birth a baby's brain, immune system, gut, myelin and organ systems are still undergoing rapid growth and development.

- Because a baby's organ systems are immature at birth, they need close physical contact, safety and attuning caregivers to regulate their physical bodies and emotional states in healthy ways, including for
  - $_{\odot}$  temperature regulation
  - heart rate
  - blood pressure
  - emotional distress
  - o sleep
- The bond between a baby and his or her parents is critical in supporting proximity, attunement and the process of physiological regulation.
- The presence of supportive adult caregivers facilitates healthy development of the social nervous system, which grows the ability to regulate in healthy, restorative ways that also minimize the need for fight, flight and freeze as a child grows and matures.
- The natural and innate ability of a mother to bond with her baby is one of the primary drives that keeps mothers and children close and helps infant nervous systems regulate their immature physiologies.
- Bonding is influenced by a mother's experiences of stress, grief and distress before conception, during pregnancy and birth, and in her baby's early life.

# Missing Experiences Affect Development Too

- The absence of formative events is also a risk factor for altering the nervous system, immune and other organ systems and consequently, for chronic illness.
- Examples of missing experiences that are designed to support health include
  - leaving the supportive environment of the womb prematurely (premature birth)
  - incubator care, which removes the baby from adult proximity and physiological co-regulation
  - formula feeding, which provides different nutrients and immune support than breast milk; formula use may also provide different physiological co-regulation between mother and baby
  - $_{\odot}$  cesarean birth, which includes
    - absence of exposure to mechanical pressure of the vaginal canal, which squeezes fluids out of a baby's lungs (among other functions not yet known),
    - lack of exposure to vaginal flora, which affects a baby's microbiome and gut flora,
    - potential situations of stress, such as if surgery is performed for lifethreatening health problems in mother or baby
    - the possibility of interfering with bonding, among other risk factors

# **Critical Periods and Type of Chronic Illness**

- The timing of exposure to environmental factors such as stress, trauma, and toxins affects organ systems that are undergoing the most growth and rapid periods of development.
- These windows of time are unique for every organ, which grows at particular times during pregnancy. These windows of influence are known as critical periods.
- Critical periods are especially sensitive in the womb and in early life when our bodies and organ systems are growing and developing at the fastest rates of our lives.
- The timing of exposure to an event most affects the organ system(s) undergoing the most rapid development at the time.
- Adverse experiences during early development can predispose us to developing one particular chronic illness instead of another:
  - The earliest exposures in the womb may set up risk for autoimmune diseases and other chronic illnesses that deeply alter physiology, cell activity and tissues to develop into easily detectable abnormalities - blood sugar levels in diabetes, gut wall infiltration in inflammatory bowel disease, heart defects, myelin loss in MS.
  - Later exposure when organ systems have developed but are refining how they operate such as later in pregnancy when a baby's body is recognizable, as well as after birth and in childhood may be risk factors for diseases of altered function that have no easily identifiable changes in cell structure such as irritable bowel syndrome, PTSD, and chronic pain.

Mini Survey: Did You Have Adverse Babyhood Experiences (ABEs)? Link to the survey in the blog post table of contents at the top of the page

#### Learn more:

Find Therapies for Healing ABEs on my Therapies Page in the table of contents.

How early life events affect risk for autoimmune & other chronic illness

How healing early trauma can cure a chronic illness: An asthma story

How early events alter our genes and explain how bonding disruptions shape health

# #2 Trauma in Childhood: Adverse Childhood Experiences Plus (ACEs+)



**Supreme Court Justice Sonia Sotomayor was diagnosed with type 1 diabetes**, the autoimmune form that requires insulin injections for survival, when she was 8 years old.

Her autobiography, <u>My Beloved World</u>, describes a childhood with parents who loved her, but who contributed significantly to her childhood trauma nonetheless. Her father was an alcoholic and her mother, a nurse, coped by working night shifts and spending as little time at home as possible.

She and her brother were ordered to use the elevator in their apartment building because addicts regularly shot up in the stairwells, where their mother was also once mugged. Her father died when she was 9 years old, to which her mother responded by drawing the curtains and locking herself in her room, leaving her kids on their own for weeks.

- The events that Justice Sotomayor experienced are more common than we'd like to believe.
- They are also all examples of trauma and are risk factors for chronic illness.
- Hundreds of adverse childhood experiences (ACEs) studies have clearly shown that 10 types of trauma experienced between birth and 18 years of age greatly increase risk of developing a chronic illness. Sonia Sotomayor's score is at least 5 out of 10: father with substance abuse problems; his early death; mother with incapacitating grief; emotional neglect; and physical neglect.
- An ACE score of 2 increases the risk of being hospitalized for an autoimmune disease by 70% or more, compared with an ACE score of zero.
- With every additional ACE after 2, risk of developing an autoimmune disease rises another 20%.
- Risk increases with each additional type of trauma for other chronic illnesses as well as mental health conditions, addictions, and many other health problems and life challenges.

Other types of trauma in childhood also increase risk for chronic illness - these include

- accidents
- serious illness in a child or family member
- poverty
- natural disaster
- being bullied
- hospitalization
- surgery
- and more

As with all types of trauma, many kinds of adverse events in childhood are simply a part of being human (accidents, loss of loved ones, exposure to natural disasters, etc).

- Parental ability to provide safety, context, connection and repair after conflict or trauma are all *powerful antidotes that counteract many such kinds of trauma and enable children to heal and recover*.
- Abuse and neglect in all its various forms, however, are routinely overlooked in our society as a whole and require much greater prevention, awareness and action because they are perpetrated by the very individuals who are supposed to protect us.
- It is possible to heal the effects of early trauma, even when it happened years or decades in the past. This is because of the plasticity of our nervous systems and the reversibility of epigenetic changes.
- I have named this category adverse childhood experiences plus (ACEs+) to build on the existing ACE studies to include a broader set of events that may be traumatic.

Take the mini survey to get a sense of how many of us have experienced trauma or adversity in childhood.

# Mini Survey: Did You Have Adverse Childhood Experiences Plus (ACEs+)?

Link to the survey in the blog post table of contents at the top of the page

#### Learn More:

Find Therapies for Healing ACEs+ on my Therapies Page in the table of contents.

Calculate your ACE score and learn about the ACE studies

Video: When You Have a Chronic Illness and A History of Trauma (It's Not Psychological) Transcript, Includes Resources

Download an ACE fact sheet + see lists of the chronic diseases affected by childhood trauma

Books and Therapies for Healing Nervous Systems Perceptions of Threat

# #3 Adverse Childhood Relationship Experiences (ACREs)

# Attachment, Developmental & Complex Trauma



Justice Sonia Sotomayor experienced emotional neglect and developmental trauma in her relationship with her parents. This began before and continued long after the onset of her diabetes.

"However much was said at home, and loudly, much also went unsaid, and in that atmosphere I was a watchful child constantly scanning the adults for cues and listening in on their conversations. My sense of security depended on what information I could glean, any clue dropped inadvertently when they didn't realize a child was paying attention."

"In the days and weeks following [my father's] funeral, the release and relief I felt from the end of the fighting gave way to anxious puzzlement. At nine, I was equipped to understand loss, even

sadness, but not grief, not someone else's and certainly not my own. I couldn't figure out what was wrong with Mami, and it scared me. Every day Junior and I came home from school to find the apartment quiet and dark, with the curtains drawn."



- A child and her social nervous system develop their sense of safety in the world from how they are parented and what their earliest environments are like (safe neighbourhoods vs war zones).
- When children experience a loving, nurturing, supportive relationship with their parents, they develop resilience and their social nervous systems gain the ability to regulate and inhibit too much fight, flight and freeze. They cope with stress because they have enough support. They have someone to talk to who will help them learn to identify and integrate

what they are feeling, feel their feelings and express them in healthy ways, figure out what to do in difficult situations, and who will protect them in times of threat or danger.

• The *absence* of these supportive elements has an effect as powerful as the *presence* of overt trauma. It is therefore called attachment or developmental trauma, or referred to as complex PTSD. Psychologist Jonice Webb, who focuses on this area of trauma, refers to it as Childhood Emotional Neglect or CEN.

I use many of these terms interchangeably. Because I'm looking at the role of many types of trauma, however, and because of the large amount of research already done with adverse childhood experiences (ACEs), I use the term adverse childhood relationship experiences (ACREs) as well. This provides some consistency with the other terms I'm using in the Chronic Illness Trauma Studies surveys here and in other posts.

A few more important details about ACREs:

- Developmental trauma is one of the most invisible and difficult types of trauma to recognize in our own lives.
- This type of trauma reflects exposure to ongoing, daily exposure that persists for months and years and shapes our entire development.
- Because of the prolonged exposure, this type of trauma is one with the most insidious and long-lasting effects on health.
- By instilling an inherent lack of safety, attachment trauma directs our nervous systems in directions of fight, flight and freeze rather than safety and calm.

We have difficulty recognizing developmental trauma because it's all we've known in our personal lives. And because our society doesn't recognize the very real and serious long-term effects of being ignored, given the silent treatment, told we were difficult or "the problem" and more - and how they erode self-confidence and the development of a calm nervous system that is resilient to life's ups and downs.

Attachment trauma increases our body's sensitivity to stress and is also a risk factor for childhood symptoms such as

- frequent ear and other infections
- asthma
- stomach aches and other general symptoms of malaise
- difficulty concentrating, learning
- problems in school, acting out
- stealing, violence
- and more

Parenting may be one of the most difficult tasks of a person's life. It doesn't have to be perfect, however, to optimize long-term health.

• The ability of parents to repair misattunements, help their children identify and regulate difficult emotions, and feel safe can be among the most important sources for developing a healthy social nervous system function and health.

• Parents can support their children's health and decrease their own and their kids' risk of long-term health conditions by recognizing and healing the effects of their own traumas, which affect how they parent.

Take the mini survey to get a sense of how many of us have experienced trauma or adversity in our earliest relationships.

# Mini Survey: Did You Have Adverse Childhood Relationship Experiences (ACREs+)?

Link to the survey in the blog post table of contents at the top of the page .

#### Learn more:

Find Therapies for Healing ACREs on my Therapies Page in the table of contents.

Attachment Trauma: Invisible ACEs

# #4 Adverse Pre-Onset Experiences (APOEs)

# Stress & Trauma in the Period Before Onset of Chronic Illness



As with recognizing other forms of trauma in my life, it took me many years to recognize events that triggered the onset of my chronic fatigue. I mention many in my story. One that took me a long time to recognize was the stress and trauma of medical training, which involved not only long and exhausting hours but also the witnessing of death, trauma and loss. Even more traumatizing for my sensitive, earnest self who had learned to please others and be "nice" as a way of coping with vulnerability early in life, was the shaming hierarchical system of often overtired senior residents and short-tempered faculty who made me feel small, weak and a failure when I didn't have answers. The long hours, ongoing stress, shame and more were triggers for the onset of my first symptoms of chronic fatigue (you can read my onset story of how my symptoms first started).

- One of the effects of unresolved trauma is to make us more sensitive to stress and other types of potential threat including infections, toxins, other trauma and more. The underlying intelligence is to enable our bodies to react more quickly upon future exposures or encounters as a means of improving our chances of survival.
- The varying length of time between exposure to an environmental stressor such as an accident, a hospitalization, rape, or the loss of a loved one and the onset of a chronic illness is known as a latency period.
- Latency periods are highly variable and are different for every person.
- Latency periods are also a known characteristic of trauma.
- The overt symptoms of chronic illness often develop after a period of physical or emotional stress such as an accident, caregiving for a loved one, losing a parent, or exposure to an infection, vaccine or other toxin.
- Onset can begin very suddenly, such as within days or weeks of an infection or a significant traumatic event or very gradually, such as 1-2 years after caregiving for a loved one or having surgery.
- The variability in latency period durations reflects how slowly or how fast the underlying changes in physiology are occurring. More traumas in our histories usually leads to a faster onset of disease. A more serious or intense traumatic event such as a car accident in which someone dies or is seriously hurt can also lead to a shorter latency period before onset.
- The event that triggers the onset of a chronic illness is generally not the cause of a disease, but the last in a series of events that have occurred over years or decades.
- If treating the risk factor that triggered the onset of a chronic illness infection, stress, toxins is not effective, look for a history of prior trauma.
- Healing the effects of unresolved trauma decreases our nervous system sensitivity to stress and other traumas as well as to other forms of threat. It can therefore decrease symptoms.
- It is possible to heal from the effects of trauma, even if it happened in childhood or before birth.
- Take the mini survey to get a sense of how many of us have experienced trauma or adversity in the 2 years before the onset of your chronic illness or other chronic health conditions if you have had any.

Mini Survey: Did You Have Adverse Pre-Onset Experiences (APOEs+)? Link to the survey in the <u>blog post</u> table of contents at the top of the page

#### Learn more:

Find Therapies for Healing APOEs on my Therapies Page in the table of contents.

Ever Wonder if Trauma or Stress Can Trigger Chronic Disease?

Trauma Triggers Type 1 Diabetes (A Research Review)

Treating Chronic Illness #9: Intuition, and Why I Left Medicine

Trauma May be an Important Cause of Type 1 Diabetes: Dan's Story & Symptoms

# #5 Adverse Multigenerational Experiences (AMEs)



#### Justice Sonia Sotomayor's parents both experienced significant trauma in their

childhoods. Her parents had financial struggles as they worked to create a home for themselves and their children. In addition, "my mother's birth, in 1927, was bad news. It was the reason, or at least the occasion, as she understood it, for her father's abandonment of the family."

Her own mother was sick, an invalid, as far back as she could remember. Sonia's mom lost her own mother when she was 9 years old, living in a family that forever struggled financially and being raised by her 5 siblings.

Her father 's dad also struggled with alcoholism and died from tuberculosis when her father was 13 years old. Her dad had to become the man of the house and his mother kept him by her side until he was 22, preventing him from accepting a scholarship for his math abilities. He went only as far as the 6th grade.

Justice Sotomayor's parents experienced devastating trauma in their childhoods, from which they did not recover. It affected their emotional health, behaviors, finances, and ability to attune, care for and protect their children.

- Trauma that our parents, grandparents and other relatives experience affects not only their own lives and health, but as Justice Sotomayor's story shows so clearly, it also shapes the lives of their children and grandchildren.
- An understanding of how ACEs and other types of trauma alter our nervous systems to shape health, behaviors, emotions, addictions and more enables us to shift from positions of blame towards past generations to a bigger picture that provides context and opportunities for healing.

Psychiatrist Rachel Yehuda's research with children of Holocaust survivors has shown that children of traumatized parents experience everyday stressors as traumatic.

- Transmission of multigenerational trauma occurs through epigenetics, in which life experiences that alter small chemicals that attach to DNA are transmitted to children along with genes.
- Transgenerational trauma is also transmitted or prevented based on the degree to which parents are able to bond with their children and by the ability of parents to repair misattunements throughout childhood (see more in #1 Trauma in The Womb, Birth & Infancy and #3 Trauma in Early Relationships).
- The effects of trauma in our ancestors' lives sometimes show up in more obvious ways in our own lives. We may, for example, experience similar traumas at similar ages such as Justice Sotomayor, who was 9 when her father died, which is the same age her mother was when her own mother died).
- We tend to raise our children similarly to how we are raised unless we have the awareness or desire to do it differently. This is another way in which multigenerational factors can subtly increase or decrease risk for chronic illness.

Understanding how trauma affects multiple generations helps us see the importance of becoming trauma informed as individuals, and also as a society and in medical care.

As with all other forms of trauma mentioned here, our bodies and nervous systems have a deep and innate capacity to recover from even the effects of multigenerational trauma.

Take the mini survey to get a sense of how many of us have experienced trauma or adversity in the 2 years before the onset of your chronic illness or other chronic health conditions if you have had any.

# Mini Survey: Did You Have Adverse Multigenerational Experiences (AMEs+)?

Link to the survey in the <u>blog post</u> table of contents at the top of the page

#### Learn more:

Find Therapies for Healing AMEs on my Therapies Page in the table of contents.

<u>Video: Multigenerational Trauma and Birth Events are Risk Factors for Chronic Illness (It's Not</u> <u>Psychological</u>) (Transcript with Resource)

RA and ME/CFS: Transgenerational Trauma and Ghosts in My Family Tree

Multigenerational Trauma: a Book Interview with J Dylan Yates

# #6 Adverse Institutional Experiences (AIEs)



Olympian and tennis great Serena Williams gave birth to her baby girl Olympia in September 2017. At the time she experienced a series of adverse events that reflect subtle, common yet often invisible forms of systemic trauma. An interview in Vogue describes how Serena first had an emergency cesarean because of concerns for her baby's safety from decreases in heart rate during contractions. The surgery itself went well but was an emergency surgery nonetheless, which can be highly stressful for some and traumatic for others.

When Serena became short of breath the day after her surgery, she immediately assumed it was a blood clot in her lungs and told the nurse she had had a pulmonary embolism in the past. In fact, she had had to go off of her blood thinners for her surgery. "The nurse thought her pain medicine might be making her confused. But Serena insisted, and soon enough a doctor was performing an ultrasound of her legs. 'I was like, a Doppler? I told you, I need a CT scan and a heparin drip,' she remembers telling the team. The ultrasound revealed nothing, so they sent her for the CT, and sure enough, several small blood clots had settled in her lungs."

- The experience of being doubted, dismissed, humored or ultimately harmed in by medical professionals and other people in positions of relative power is a common, subtle form of trauma. It occurs throughout our institutions here in the United States:
  - $_{\odot}$  medical and mental health care and institutions
  - how we <u>treat and care for children in general</u> in our country
  - foster care
  - $_{\circ}$  adoption
  - government policies such as the current immigration practice of <u>separating</u> <u>parents and children</u>
  - $_{\odot}$  schools
  - type of sentencing we give children for crimes
  - quality of care we give children & adults in prison and detention
  - our care of the environment, which is a source of safety for all and for future generations
  - $\circ$  and many others
- Despite Serena being a former Olympian and star of epic proportions, and irrespective of her past medical history for this specific issue, her statement was treated with unconscious bias.
- It was also overlooked despite many other known medical facts, such as:
  - having been on a blood thinner for this problem at the time she was hospitalized
  - $_{\odot}$  having been taken off her blood thinner for her emergency cesarean
  - o describing clear symptoms of shortness of breath
  - the well-known surgical fact that pulmonary embolism is one of at least 3 common events to watch for in the days following any type of surgery [I learned this as a medical student]
  - the also well-known fact that blood clots are also common in pregnancy

Similar to often unacknowledged developmental trauma in which children are not treated as full human beings with the right for respect, care and safety, systemic trauma is built on blind spots, individual and societal histories of trauma, and lack of awareness.

- As an African American woman, Serena represents minorities who experience culturewide discrimination and microaggressions at work, at home, in leisure activities, in health care and beyond for characteristics attributed to their person: gender, race, religion, ethnicity, sexual orientation, ability & disability, health, financial status, and more.
- It should come as no suprise, then, that systemic trauma is another <u>risk factor for disease</u>.



• Whether Serena's being doubted was related to her gender, religion, the color of her skin or some other factor isn't known, but the statistics show that systemic <u>racism</u> has a profound effect on health, including in maternal care:

black mothers in the U.S. die at three to four times the rate of white mothers, one of the widest of all racial disparities in women's health. Put another way, a black woman is 22 percent more likely to die from heart disease than a white woman, 71 percent more likely to perish from cervical cancer, but 243 percent more likely to die from pregnancy- or childbirth-related causes.

In a <u>national study</u> of five medical complications that are common causes of maternal death and injury, black women were two to three times more likely to die than white women who had the same condition." (quoted from an article by <u>NPR-Propublica</u>)."

Native Americans also suffer from higher rates of <u>these problems</u> than whites, as do some groups of Latinas, and <u>maternal mortality rates are also rising in the U.S.</u> for white women, suggesting other cultural and medical bias based on gender as well as race.

- Some kinds of chronic illnesses are more common in certain populations, suggesting links perhaps to genetics, but also to historical and often ongoing system-wide trauma:
  - Diabetes, obesity and metabolic syndrome in Native Americans (loss of lands, homes and personhood)
  - Lupus in African Americans (slavery / oppression the need for the Black Lives Matter movement)
  - Inflammatory bowel disease in people of Ashkenazi Jewish descent (the Holocaust, pogroms, long history of other prejudice),
  - Autoimmune disease (gender discrimination, sexual violence against women but also against men - the need for and unexpected efficacy of the <u>#MeToo</u> movement...)
  - $\circ$  and more.
- Serena's history of pulmonary embolisms happened after she slipped on a piece of broken glass at a Munich restaurant, which could have been a traumatic triggering event. Her older sister Venus was diagnosed in 2011 with the autoimmune disease called Sjogren's, which is sometimes linked to other immune system diseases such as lupus. Additional history of trauma includes the fact that they had an older sister, Yetunde Price, who was murdered in a drive-by shooting in 2003.
- While institutional trauma needs to be addressed at a systems level in order to change our practices, recognize trauma and implement prevention strategies throughout our society, individuals and communities can make significant differences in health outcomes starting now and not having to wait for these changes to take place.

Take the mini survey to get a sense of how many of us have experienced the effects of the often subtle, very subjective and difficult-to-quantify effects of institutional trauma and discrimination.

Mini Survey: Did You Have Adverse Institutional Experiences (AIEs+)?

Link to the survey in the <u>blog post</u> table of contents at the top of the page Adverse Institutional Experiences (AIEs)?

**Empowerment Tools:** 

Find Therapies for Healing AIEs on my Therapies Page in the table of contents.

Chronic Illness ACE Fact Sheets To Educate Your Doctor (Free Downloads)

<u>Create a 1 Page Medical History That Will Empower You and Help Your Doctor Listen (Free Downloads)</u>

Other Articles:

Resilience, trauma-informed care, and healing are not enough; something has got to change

Why Resilience Training Isn't the Antidote for Burnout

David Williams, a Harvard sociologist, pioneered the survey instruments that document the connection between <u>discrimination and disease</u>.

Even a single community can make differences in decreasing effects of systemic trauma.

Shifting from Trauma Informed Care to Healing Centered Engagement

# VI. Chapter 6: Understanding & Healing Trauma Improves Health

# Making Sense of Symptom Flares



When I left medicine and retrained as a somatic psychotherapist, I was reminded that it was common knowledge in psychology that reminders of past trauma are triggers for anxiety, PTSD, hypervigilance and other mental health symptoms. I wondered if similar triggers could stimulate my chronic illness symptoms. It took over a year before I noticed that a mildly conflictual phone conversation had preceded a worsening of my fatigue. In contrast to the discouragement I'd often felt with previous flares, my fascinated research-minded inner nerd was ecstatic to having finally caught a trigger red-handed. And as this entire post emphasizes, this psychological conflict reflected a traumatic nervous system pattern rather than a psychological cause to my illness.

- Triggers are reminders of adverse life experiences and unresolved trauma.
- When we are exposed to a trigger, we experience symptoms that are similar to what happened during the event itself such as fear, shaking, sweaty palms, racing heart or the feeling that you are in the traumatic event as if it were happening in the present moment (a flashback).
- Triggers are unique for each one of us and are based on our specific past experiences.
- Triggers stimulate underlying states of fight, flight and freeze that the nervous system maintains when trauma is unresolved.
- If you were once traumatized because you were threatened by a volcano eruption, for example, you might experience symptoms on a smoky day, on hearing the explosion of a car backfiring, or when sitting by the heat and flames of a campfire.
- Every exposure to a trigger increases our sensitivity to the next ones.
- Every exposure to a trigger increases the speed and intensity with which the underlying trauma patterns arise. This is how our nervous systems modify themselves to maximize survival in the event we encounter this traumatizing experience again in the future.
- Triggers therefore increase our symptoms of chronic illness as time passes when trauma remains unresolved.
- Over time, triggers that stimulate symptoms become smaller and less recognizable as our nervous systems become more sensitive to reminders of past events. This is known as "kindling," referencing the small sticks that make it easier to light a fire.
- If you have a symptom flare, chances are that you have been exposed to a trigger. You may be aware of the trigger if you understand trauma, or it may be too subtle to detect. It can still take me hours or days to recognize that a symptom flare isn't just because I've overdone it, but because I got triggered.
- Triggers, like trauma, tend to be difficult to recognize because they are held in our unconscious, deep within our brains to protect us from fear and overwhelm. This is the nature of unresolved trauma.
- Looking for triggers, understanding how they affect us, and working to heal the effects of past traumas all help identify and defuse their effects, including symptom flares.
- Triggers are another element showing us the links that exist between chronic illness, trauma and the nervous system and to events that happened in the past.

# Learn more:

Find Therapies for Healing on my Therapies Page in the table of contents.

How Flare-Ups Can Offer Powerful Clues For Living With Chronic Illness

A collection of posts on how I work with my symptoms from a trauma perspective

# Healing the Effects of Trauma

# **Healing Chronic Illness**

#### **Reinstating Nervous System Balance**



# Restoring the social nervous system's ability to inhibit and regulate fight, flight & freeze helps our bodies heal.



- We are more than our chronic illnesses.
- We are bigger than what happened to us.
- But understanding and talking about trauma is an important step towards healing, especially if nothing else works and no other options exist.
- It's also a helpful adjunct to anything and everything else you do to work with your symptoms.
- Once we understand the role of the nervous system, brain plasticity, epigenetics and more, we can -
  - learn to identify new treatment tools
  - test new tools from a useful perspective
  - understand effects of treatment
  - determine which side effects are signs of healing and which are indicators of retraumatization
  - begin to heal

**Healing the effects of trauma - like quelling a volcano - takes courage, perseverance, and time.** Courage because it can bring up painful feelings that have long been held back - although somatically trained trauma therapists have many skills to minimize overwhelm and keep what arises within manageable, digestible doses. Perseverance and time because it's not always clear that trauma therapy and other approaches that support nervous system healing are working. Our

symptoms may sometimes get worse at first. And the first symptoms to heal may be emotions, before our physiologies begin to shift and heal as well.

But the gifts of healing are worth every action we take, as I've repeatedly found over the past 10 year. The evidence from all the things I've tried has lead me to focus increasingly specifically on trauma healing as my main tool for recovery.

And I get a little better every year. 9 years ago I was essentially bed-ridden. Today I have the energy to run errands, cook my meals, plant in my garden if I space it out over time, and take long walks. I'm not fully recovered and would not be able to work AND do all these things yet, but I now suspect that it is possible to someday return to work and to a full life. And that it's just a matter of time.

# Tools for Healing & Resolving Effects of Trauma:

<u>Books & Therapies for Chronic Illness:</u> Healing Nervous System Responses to Stress, Trauma (and Perceptions of Threat)

Making Time for Chronic Illness Resources

Create a 1 Page Medical History That Will Empower You and Help Your Doctor Listen

Chronic Illness ACE Fact Sheets To Educate Your Doctor (Free Downloads)

Life-Altering Perspectives In Disease Treatment

A Collection of Posts on how I work with my symptoms from a trauma perspective

#### Other Article:

• <u>On Midlife, Midlife Unraveling, by Brene Brown</u>

# Healing our Institutions Improves Health for All



# When we understand how trauma works, we can begin to make changes as communities, and as a society.

While gaining tools for healing ourselves is where we currently need to start as individuals who already have a chronic illness, what really needs to happen is systemic change.

We need to change how we treat and support children, parents and families.

And we need to recognize and prevent trauma so that the burden does not fall so completely on the millions of individuals who then spend years, decades and often lifetimes suffering, or trying to find ways to heal and recover, often at great financial and emotional cost.

These growing insights are starting to change how medicine is practiced and how we understand and treat illness. It's happening slowly but truly, with:

new medical guidelines being developed by the American Academy of Pediatrics with tools for assessing toxic stress (ACEs), a trauma guide and publications about ACEs and effects on risk for long term health and chronic illness ((Garner, A. S., et al. (2012). "Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health." Pediatrics 129(1): e224-231)), ((Shonkoff, J. P., et al. (2012). "The lifelong effects of early childhood adversity and toxic stress." Pediatrics 129(1): e232-246)).

- research presented on <u>Stanford's website</u> ((Rappaport, S. M. (2016). "<u>Genetic Factors Are</u> <u>Not the Major Causes of Chronic Diseases</u>." PloS One **11**(4): e0154387))
- a <u>Harvard</u> program studying effects of early treatment and prevention for children
- a study at <u>Columbia University</u> looking at effects of early treatment and prevention with moms and their premature babies
- the formation of <u>ACEs Too High news site</u> about adverse childhood experiences
- implementation of trauma-informed practices in medical clinics
  - for kids in Oregon, at Kaiser in northern <u>California</u>, and in <u>the San Francisco bay</u> area ((Burke Harris, N. (2018). <u>The Deepest Well</u>: Healing the Long-Term Effects of Childhood Adversity, Houghton Mifflin Harcourt))
  - for adults in one of the Kaiser centers in southern California ((Felitti, V. J. (2002).
    "The Relation Between Adverse Childhood Experiences and Adult Health: Turning Gold into Lead." The Permanente Journal 6(1): 44-47))
  - in pregnancy care for moms and babies in <u>Cleveland</u>, Ohio and <u>Winter Garden</u>, Florida
  - at the <u>community level</u> in Washington, Minnesota and Pennyslvania, among others.

# **Chronic Illness Trauma Studies**



# A Blog About

- How Nature & Nurture Interact to Shape Health
- The New Research
- The Role of the Nervous System in Disease
- The Chronic Illness Trauma Connection
- How Trauma Science Makes Sense of Symptoms
- Tools for Healing
- · What I've Learned from My Own Chronic Illness

It is possible to heal the effects of unresolved trauma & thereby support our body's innate drive towards health.



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# References

1. Rappaport, S. M. (2016). "Genetic Factors Are Not the Major Causes of Chronic Diseases." PloS One 11(4): e0154387 see more in Rappaport & Smith

2. Garner, A. S., et al. (2012). "Early childhood adversity, toxic stress, and the role of the pediatrician: translating developmental science into lifelong health." Pediatrics 129(1): e224-231

3. Shonkoff, J. P., et al. (2012). "The lifelong effects of early childhood adversity and toxic stress." Pediatrics 129(1): e232-246

4. Rappaport, S. M. (2016). "Genetic Factors Are Not the Major Causes of Chronic Diseases." PloS One 11(4): e0154387

5. Burke Harris, N. (2018). The Deepest Well: Healing the Long-Term Effects of Childhood Adversity, Houghton Mifflin Harcourt

6. Felitti, V. J. (2002). "The Relation Between Adverse Childhood Experiences and Adult Health: Turning Gold into Lead." The Permanente Journal 6(1): 44-47