

Chronic Pain~ from Inflammation & Behavior

A Newsletter from Robert Gallup, Ed.D.



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Heather's Story: Healing Chronic Pain and Chronic Fatigue "My Experience, Strength, and Hope!"

The Newsletter usually starts with a lead article detailing or summing-up an historical development or critical concept in Psychoneuroimmunology (PNI). This issue is honored to lead with the powerful story of and by "Heather," whose life-long struggle to overcome chronic pain and chronic fatigue is unfortunately typical in symptoms and background. It is extraordinary in terms of her courage, insight, and healing. Today, it is scientifically well accepted that the "stress response" is an integral part of the "immune response" (and visa versa), because the immune and nervous systems are functionally enmeshed. Neglect and abuse result in conditioned chronic inflammation, with symptoms such as fatigue and pain. Frequently this is a life-long problem. However, Heather is changing her health behaviors. Clearly, she is healing!! Below, she shares her experience, strength, and hope. Her story is a wonderful example that **the-only-way-out-is-through.**

"Mommy is going to lay down for a little while"

Migraines impacted my life for years by immobilizing me and making me physically ill. Often I would be curled up in a fetal position in a dark room devoid of sound and light and lying very still. This was difficult as a single parent knowing that my two young boys were probably frightened to see Mommy like this and yet they had the run of the apartment. Sometimes a cold compress would help, but it was hard to get up and change the cloth because any kind of movement would intensify the pain.

I still get the same headaches today, though not with the same regularity. I usually end up sleeping upright on the couch, whimpering a desperate prayer to God to relieve me of the pain. I've noticed my thoughts during a headache and they are usually related to traumatic flashbacks. I struggle to try to change these thoughts that I'm dwelling on.

Fatigue and shortness of breath in the beginning would annoyingly occur during routine household chores (washing the floor, doing the dishes, cooking supper) and I can remember many a night telling the boys, "Mommy is going to lay down for a little while" and I would fall into a deep sleep for hours. This still happens sometimes and it is when people are talking to me or I am watching a program with friends. One

The next issue:

- The Biology of "Chronic" Inflammation
- Healing Happens! (case study)
- Guest Contributor

minute I am awake and the next I am not. Sometimes during long conversations, it feels as though my brain shuts off and then I tire easily. I do best in quiet environments. I am learning to change what I am eating. I am educating myself today on what the brain needs nutritionally to function properly. I was nutritionally illiterate for years living on social assistance. Remarkably a recent study has revealed that low income women are more likely to develop CFS/FM.

I am learning to pace myself, resting before and after some activities, I find that sometimes I am blessed with more energy and can enjoy a walk or the stamina to do several loads of laundry. One must be careful not to overdue during this episodes as it is easily a way to relapse.

Knowing that I have CFS has helped a lot

There was a period of time in the beginning of my diagnosis were I was bedridden and that was scary, I didn't have the energy to dress or anything. If my boys, or my husband at the time, would sit on the bed just to be close to me, my whole body would hurt. Though the phone lay on the bed next to me, during that time I did not have the energy to lift the receiver. It was scary because I never understood what was happening within my body. I have been informed recently that professionals did not have any information to educate me. The doctor who diagnosed me had CFS himself and immediately sent me for an MRI which showed conclusively that there had been organic changes in the brain, though no one took the time to help me understand how that happens.

Cognitive difficulties have always been a problem and it was only a decade after my diagnosis that I learned what it meant to be told that my mental processes would become considerably slower when emotionally overwhelmed. It meant that I would not understand the concept of what was happening to me. It has been frightening not knowing what I was experiencing, repeating conversations and not remembering previous conversations. It always makes me cry because I find myself repeating conversations and having no recollection of those conversations or appointments made or missed. I write everything down and need to carry a written calendar with me and sometimes that doesn't help.

A common foundation for CFS and chronic pain: childhood abuse and neglect

For most of my life, I have lacked the consistently supportive adults who would be available to teach me the skills I required to process incidents of grief and loss in my life. Due to this lack of support and the missing skills needed I stumbled through my childhood, adolescence and sadly most of my adult life in ignorance accumulating incidents of unresolved grief and distorted perceptions about myself and the world in which I lived. I routinely found myself bewildered and fatigued, mentally and physically, not understanding many of my emotional experiences.

At the tender age of twelve while playing on the playground of my grade school, my friends began to taunt me about the fact that I really had no parents. I was adopted. Did I laugh the first time they said something so ridiculous? I can't remember, but as they continued their taunting, confusion was ignited in my mind that day. Why were my friends saying such hurtful things? Years later, I would come to understand that they were simply repeating whispered conversations that they had overheard their parents talking about at home. My friends were hauled into school before recess was over and reprimanded, and I was sent home hysterical. My resources for managing any kind of emotions were almost non-existent and I struggled to make sense out of what my friends had been trying to tell me.

When I arrived home from school that day (some memories are as clear as if they just happened) no one was

emotionally available to me or concerned about my upset or able to answer my desperate questions. My feelings were not encouraged to be felt and my adoptive father said simply, "Kids can be cruel." Bewildered, I picked up a book and lost myself thinking about something else and later, began my first journal as the pages seemed to absorb my feelings and provide a physical release of identifiable feelings. Often when I speak about these things, a headache will develop and my throat will close.

Frozen feelings can result in fatigue and pain

So many memories lay hidden deep within my heart and later in my life, I would meet a wonderful woman, a Certified Grief Therapist, whose office would provide a safe place to begin to talk about these incidents. I found that the buried feelings contained the intensity of that particular time and in speaking of these things for the first time frozen feelings seem to thaw with the empathy of my therapist, and to begin ever so slowly to flow from me. Though sitting through those sessions as a fifty year old woman, my feelings made me feel like a little girl all over again. Although bewildered, I found the courage to sob my little heart out. My grief-therapist, was tender in validating how painful each circumstance must have been for me. I felt heard for the first time. Someone understood and acknowledged those troubling things in my life. I cried louder and louder.



I can remember many nights having been sent to my room as a wee girl for something and creeping out of my room to the top of the staircase where I would perch listening breathlessly to my parents argue about why they had adopted someone else's child. I slipped back to my room each time, blinded by tears. I would scribble down distorted messages about myself that I was unconsciously creating because of what I had heard but really didn't understand. Was I defective? More questions took root in my little heart and I wondered if there something wrong with me? Was I defective in some way?

My adoptive parents had originally been told by doctors that they could not conceive their own children, but by adopting me they were in time blessed with their own natural sons, miraculously. Sometime after my brothers arrived I felt as though my purpose in the family had been served and I was regulated to outside the perimeter of my family. I grew up identifying as a little homeless waif peering into brightly lit rooms wishing I belonged to the family by the hearth. I grew up feeling unloved, rejected and defective as a little girl. Each subsequent loss of any kind affirmed that something was indeed wrong with me. I grew up believing that my needs were not important to anyone else and that nobody loved or cared about me.

Sometimes my adoptive mother would get angry or frustrated with me and mutter another name under her breath. The name that I was born with had been changed when I was adopted at the age of six months and it was my birth name that my mother would whisper like a curse in frustration.

Chronic inflammation from puberty

From twelve years old I suffered with physical problems like migraine headaches, skin rashes, asthma, pneumonia, and later would develop CFS/FM. What I didn't know then is that my suppressed emotions were registering in my body as illness. The truth is that our cells store every emotional experience we've ever had. Memories unresolved carry the unspoken energy of each circumstance. Thus, I was a walking mine field, and to some extent I still am lacking the skills to identify my feelings and to process them in a healthy way. Current situations would trigger an explosion of feelings or illness (depending on whether or not I felt safe discussing how I was feeling).

I remember visiting the adoption agency which had handled my adoption in 1956 in a nearby city and having my adoptive mother tell me horrendous stories about the possible circumstances of my birth (i.e. my mother being a prostitute), and what if I was the product of some stranger? She painted a very dark and foreboding picture for me out of her own insecurities about possibly losing the child she had adopted and cared for as her own. I remember receiving the non-identifying information from the social worker and being relieved that the circumstances of my birth were nothing like my adoptive mother had described to me. I remember leaving that building and remarking how radiant the sun appeared to be that day simply because I had found a piece of my puzzled existence within the building.

While I sought my birth family, my adoptive parents locked me out of my adoptive family for a period of two years. They often threatened to write me out of my father's will but the desire to know something of my birth family propelled me forward and I was willing to risk emotional abandonment. I have since learned that the yearning to know one's birth parents is a normal desire for most adopted children.

The night before I married my first husband, John, my parents announced that they would not be attending the blessed event as they didn't feel as though it was their place to be there as there were not my real parents. I was devastated. I struggled to catch my breath and to quickly think of how we would afford everything in so short a notice. My adoptive father had called the manager of the hotel where the reception was scheduled and told him some story about "us kids" wanting to pay for our own wedding. It was a total shock to both of us and we scurried around from finance company to finance company hoping to secure a loan, which we did successfully. The memory is clear in my mind as though it happened yesterday. I learned that because my parents were not attending that many of our relatives also did not attend out of some misguided loyalty to my parents. I was heartbroken on what should have been the happiest day of my life. I do remember several happy times, but those memories are overshadowed to this day by the wounds I received.

Knowledge of PNI is helping me to heal

Sadly, at an early age, books were much more readily available to me than people to talk with about how I was feeling. I am an avid reader today and consider myself a lifelong learner. Today, I pursue an avid interest in PNI because it helps me to understand the biochemical impact of all that I have ever experienced and the profound impact on my body, mind and spirit. What I begin to understand dissolves my anxiety and insecurities. Over time I can integrate the new awareness and the information helps me to reframe and change my immature interpretations of who I've always imagined myself to be. Today, I am blessed with a circle of supportive friends who have taught me about healthy love. Through their loving me, I am beginning to heal my perceptions of myself and to begin to love myself and the wonderful woman I am becoming.



I hope to publish my journey with disenfranchised grief (that grief which society does not recognize) in order to help educate and give hope to others who might now be stumbling about in the same ignorant darkness. With what I am learning about myself, my positive emotions and the physiology that they can create I believe that one day I might become truly healthy and experience the joy of working full-time like everyone else around me. Living in a vortex of confusion for most of my life has been challenging and very difficult without

the skills I needed but a strong faith in God has kept me moving forward step by step believing faithfully that brighter days lie ahead of me.

When I let go of what I am, I become what I might be.

~Lao Tzu

My name is Heather. I am a fifty-one year old woman who has suffered with CFS/FM for the last thirteen years. I am a mother of two sons. Finding this Newsletter and its website has provided great encouragement to me. It is both an act of healing and an honor to write this article.

The message of a birthday card I received last year helps inspire me to believe in the possibility of changing my physiology today. The message reads:

“Long ago, there was a plan that God put into action for a little girl to be born who would grow up to be strong and full of faith and fruitful in beautiful ways. A little girl who would become the wonderful woman that I am becoming today.”

Heather in PNI

The good news about Heather's story is that PNI can now provide biological and holistic explanation for the damage, symptoms, and recovery. In my view, her story illustrates very well some of the most important and useful principles/theory from PNI. Also, recent findings in PNI which add to this theory/principles applicable to understand Heather, are presented in the next articles.

The Set-up and Organic Damage:

- ◇ The inflammatory response is an integral part of the stress response. Psychosocial stress can induce inflammation any where in the body, especially the brain. Emotional abuse, lack of love, and general absence of emotional safety cause chronic inflammation. **Our brains are mostly immune cells**. They outnumber nervous cells as much as a hundred to one, depending on location.
- ◇ As the days, months, and years of the abuse-loss-fear/stress went on Heather's immune-nervous system became more and more sensitive and reactive to smaller and smaller amounts of stress. The result can be called a **conditioned response** and/or “sensitization processes.” This chronic inflammation does in fact cause organic changes/damage, just in the same general way that repeatedly bumping our elbow can result in a chronically and easily inflamed elbow.
- ◇ It is well known that such early experiences can negatively affect how well our bodies grow and develop> how well we can adapt to stress and changing life events. This is especially true in the development of competent immune<>nervous system function.
- ◇ It should be emphasized here that we need the positive experiences. We need to get our **real needs mostly met**, in order to develop into fully adaptable/healthy people. So, the absence of the positive is also critical to understanding individual development.
- ◇ The exact picture/symptoms from the above is individual, partly based on genetics.

Chronic Inflammation becomes a Way of Life (resulting in diagnosis such as CFS, FM, etc.):

- ◇ The symptoms of chronic inflammation (also, known as “sickness behavior”) can keep us from “feeling” like we are able to perform the healthy-behaviors we need to do. So, the cycle is maintained and the spiral is downward. The less we do> the less we do.

There are no pills, procedures, or treatments of any stripe that can break this cycle. **It is conditioned and maintained by our behavior.** Inflammatory chemicals can be induced with even the slightest challenge. The behaviors we need to do for real healing> to begin to break this cycle typically feel out of our reach.

“The Only Way Out is Through:”

Only when getting our real needs met does our body make the chemicals which provide the balance of the anti-inflammatory with the pro-inflammatory systems>real healing and Health. The behaviors we need to do for real healing> to begin to break this cycle generally are: **eat what we truly need, perform tasks which give genuine self esteem, have the exercise we need, and enjoy the psychosocial experiences we need.**

Heather did not wait to change her behavior until she “felt better.”

Heather seems to have begun her recovery by achieving a **robust Social Support Network.** These people are providing her with the emotional safety and home she may not have ever truly experienced. She feels accepted, loved, and has a place she can participate in activities which give her self-esteem. Also, she had very good luck to find a few professionals who provide her with a framework to truly understand herself.

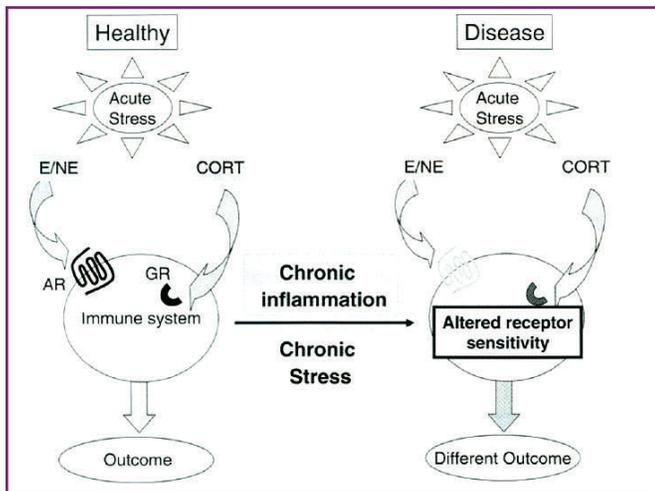
Heather is changing her diet and moving more. She is working part-time. She sees herself on the **healing-side** of these issues. **She has taken personal responsibility and committed to a path of change. I hear patience, perspective and self love in her words.**

Recent PNI Research– Applied (especially to “Chronic Inflammation”)

The purpose of this section is to “translate” recent PNI research for immediate functional use. The statements below are based on research reported recently in the Journal Brain, Behavior, and Immunity (BBI), which is the official journal of the Psychoneuroimmunology Research Society.

- Although cells of the immune system have receptors for every known hormone or neurotransmitter. The mere secretion of these chemicals by the nervous system does **not automatically** result in a predictable effect on the immune system. This is because the immune system regulates to what extent it can or will respond (for example to a “stress chemical”). The condition of the immune cell and the responsiveness of its receptors at any given moment will determine that cells response to brain signals.
- The concept of “sensitization process” is of particular importance to those who suffer with chronic inflammatory/stress-related diseases such as Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), and Post-traumatic Stress Disorder (PTSD). This concept means that the more frequently an immune or nervous cell secretes the chemicals (cytokines) which cause pain/fatigue/stress, the more likely it will happen again and again. The cell’s threshold for this secretion becomes lower. So, it takes less “stress,” of whatever kind (from various lifestyle behaviors), to induce inflammation (chronic pain, chronic fatigue, and chronic emotional stress). Please see the figure on the next page which can help illustrate this concept.
- In a summary of PNI literature from the past twenty years, BBI editors state explicitly that **individual perception of life events** drives neuroendocrine changes which can influence immune function resulting in: Wellness, recovery from disease or injury, infection, autoimmune diseases and cancer. *{I believe that this is the biological basis to say that healing is mostly an “inside job.” This is a cornerstone of my practice> assisting people who suffer from chronic inflammation to change/improve their health behaviors (for example physical activity, diet, emotional/social patterns) to promote their own healing and Wellness.}*
- The immune and nervous systems produce a common set of chemicals and receptors which provide the basis of their bi-directional communication. This is a basis of the idea that idea that the immune system

serves as a **“sixth sense.”** This “sixth sense” is able to detect what phenomena (internal and external) that our other senses cannot see, hear, smell, taste, or touch. For example, tumors and pathogens can be detected with great specificity and the body as a whole then mobilized to respond.



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Cobi J. Heijnen, p.2

- As a sensory organ, the immune system is able to detect internal and external entities so specifically that the body is mobilized to deal with/make necessary adaptations for survival and homeostasis.
- The signaling process for the above to take place involves the “molecules of information”/ligands produced by immune cells (such as pro-inflammatory cytokines), and the receptors on cells throughout the body including the nervous system. The vagal system, circumventricular organs, and nerves from the autonomic nervous system are also important parts of this communication system.
- The discovery that immune cells have receptors for all of the known neuropeptides, hormones, and neurotransmitters is a critical fact to help understand how the immune system can be called “the sixth sense” and how this may work.
- Of course, the discovery that immune cells can make

many if not most of these “neruochemicals” helps to fill out the picture and propel PNI and biomedical research in new directions.

- **AND, please remember that the most common cell type in the central nervous system is the “immune” cell such as glia. These outnumber “nervous” cells by 50-100 to 1, depending on location. These cells can and do function as macrophages do, anywhere else in the body. They are an integral part of CNS function, not just “filling” as I learned in neurophysiology class over twenty years ago.**
- Emotional stress primes glia to the presence of inflammation anywhere in the body. It appears that such “priming” sort of turns-up-the-volume in this circular relationship between inflammation (and its symptoms such as pain, fatigue, depression) and stress.
- **Stress alone is sufficient to activate microglia in the central nervous system to induce inflammation!!!**
- Stress can increase the proinflammatory reaction to an immune challenge (such as an injury, etc) anywhere in the body. This helps explain why people with chronic inflammation are so vulnerable to exacerbation, and a high baseline inflammatory-load.
- Research shows that Major Depression is associated with increased inflammatory chemicals in the blood and cerebral spinal fluid.
- A common finding in people with Major Depression is increased blood levels of C-reactive protein. C-reactive protein, is a product of the pro-inflammatory cytokine Interleukin 6 (IL-6).
- Activation of inflammatory responses stimulated by stress is exaggerated in people who are depressed.
- “Depression” shares most of the same behaviors as “sickness behavior,” which is what happens when there is chronic immune activation. Again, “sickness behavior” involves alterations in mood, motor/sensory function, cognition, and neurovegetative functions.
- Mechanisms for the above seem to involve cytokine effects on neurotransmitter and neuropeptide function, neuroendocrine function, and synaptic plasticity.
- Recently, leading PNI scientists have succinctly defined “Psychoneuroimmunology” as: “addressing the integrated nature of the relationships among behavioral, neural, endocrine, and immune responses that enable an organism to adapt to the environment in which it lives.”

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Healing Behaviors

Most importantly, our fundamental needs for food, shelter, and safety must be met.

- Willingness to take responsibility for our own behavior, including emotions.
- Cognitively framing life events, most often, in a positive light.
- Experiencing-knowing-sharing our deepest feelings.
- Connection with our communities (for example, having a sense of “purpose” for our lives).
- An individually healthy diet, which gives us the ‘right chemical in the right place at the right time.’
- Our musculo-skeletal tissue must be able to do what we do, in general, without significant strain.
- Having at least one productive activity, which gives us the experience of passionate-focus.
- Experiencing a strong sense of self-efficacy related to at least one role that is important to us.
- A personal sense of Connection to a power-greater-than-ourselves.

In order to accomplish these we often need to:

- * “Hit a bottom”
- * Seek/receive: education, information, support from friends-family.
- * Mentoring/guiding.