

CHRONOLOGY OF HEALTH Sam Cohen

Summer 1985

I am still a student at JCT (Jerusalem College of Technology), that's when it all started; Out of the blue, one day I am feeling complete loss of the present moment. Everything is experienced through a "fog".

Went to a polarity therapist who balanced my energy. He said that my "head is on fire", and that I should be more "in my body". Felt better next day, but the condition returned within a week. As of this moment my life has changed completely.

1986-90

Fog is persisting, feeling generally very weak. Saw a doctor (Dr. Zev Young, MD). Did Blood tests. Everything appears ok. He offers no solution, so I decide to see a naturopath (Dr. Francine Loeb). She in turn recommends a Chinese Herbalist (Dr. Jim Chan) to see me. He immediately diagnoses the condition as "**severe kidney Yang deficiency**" and recommends Chinese herbs (In his view, kidney yang deficiency is a very severe problem, wreaking complete havoc in a person's life, and western medicine's solution is to "trade in your body"...). Very slowly the condition improves over a period of four years (the slow rate is primarily due to having to deal with lots of stress such as tight finances, relationship issues, work that depends completely on deep thought, having my first child, and the stress of daily life in an already significantly weakened state) but never to the state prior to the incident in 1985.

1990-92

Fog is mostly cleared, but internal energy is very weak still. A new problem has come. Noticing draining of energy during conversation. First time it happened while giving a technical presentation at Boeing. After the presentation (about 45 minutes in length) I felt very bad. Overall, I notice that after a while " into" the conversation, I start draining energy. By then It's usually too late, and I am already feeling bad. I saw Dr. Liu (Chinese Herbalist) off and on for about a year, starting around the end of 1990. He recommended I practice **Tai Chi** on a daily basis to strengthen energy.

1992- 1996

Started Tai Chi, have practiced ever since(instructors Richard Airies, En Sui Puaa, Saul Krotki). Overall I have had some great experiences, but the root of the problem does not seem to be addressed. I still drain energy during speech, and every day is like walking on eggshells not to get sick. During those four years I have seen Chinese herbalists off and on. I also did acupuncture (Dr. Hoy Ping Yee Chan).

Around december of 1995, I decide again to go see an MD to check myself out. Blood tests seem ok. No answer.

1996-97

During February (97) we had several long lasting meetings at work; during those meetings I talked way longer than I was comfortably able to. I ignored inner warnings, because I thought that "it was all in my head" , even though I knew deep inside that this was real. I got sick.

After that, I stopped speaking completely.

Even uttering a word, or whispering or singing were impossible. I was very very weak. I went to see Dr. Rockwell (MD ENT specialist) to check my vocal cords. Vocal cords were alright, but the whole area was bathed in mucus. Read article about Chip Hannauer, who had Spasmodic Dysphonia, but my situation seemed to be different.

I sent out a plea for help over the internet. I feel like I may not live much longer. I meet a most wonderful person, who has helped me a lot. I learn **TM**, and try a variety of modalities. At this point I'll try anything. I do colon cleansing (Dr. saarinen), and adrenal cortical injections, magnet therapy, and brain related supplements.

In 5/97 I stop working and go on disability. The fact of going on disability, coupled with TM is wonderful. I can't praise TM enough. In 5/97 I regain partial speaking ability, after 15 months of no

speech at all. I attribute some of it to psychogenics (mind exercises that strengthen left and right brain communications).

1998 -99

The 6 months of short term disability are up. The long term disability takes time to get approved. But it is especially difficult in this case. After all, everything seems ok, and nothing abnormal shows up on any "tests". I get so stressed out over this that I incur severe relapses and lose everything I gained in terms of speech. It looks like in four months all of our savings will get depleted and we'll end up on the street. Then thank god, I do get approved, and it's back to working on my health. Around June of 98, I get diagnosed with **CFS/CFIDS (Chronic fatigue Immune Deficiency Disorder)** by an international specialist at Harborview Medical center.. This is a most debilitating condition, and has been under research for over 20 years now. Currently there is no cure. Sometimes, a major difficulty is that the person looks fine, and has good days in which he/she functions well. This makes it difficult for people to understand. In the beginning of 99 I get approved for Social Security and it takes over from the Boeing Insurance. Still this is fine.

I noticed I have a long crack in my forehead. Wonder if this is a sign of some fracture or trauma, that could be responsible for my mental function.. I have no recollection of this happening.

Dr. Waling diagnoses some form of **malfunction between left and right brain hemispheres, as well as adrenal weakness.**

Another doctor claims a **complete depletion of thyroid, hypothalamus, and pituitary glands.**

Around 1/02.

Dr. Dick Loyd, diagnosis me with a **ketogenic imbalance, and TB virus in my brain.**

Around 10/02.

Dr David Silverstein, who has known me well for three years now, recommends I urgently go to the Mayo clinic and get my brain checked..

October 2002

This is the most difficult period of all. Since April of this year I have had many relapses/flare, and lost much more health/brain power, and function. This is because the relapses are extremely detrimental, and cumulative, so that even when I recover from a relapse, I am still worse off than before the relapse.

What has happened over these last 6 months is almost as significant a loss as losing my speech in 96.

At his point, I can only focus for a few minutes at a time, so I can only interact with a person for a few minutes at a time, only think for a few minutes at a time etc. What I could do only a few months ago for 20-30 minutes, is now unfortunately gone. I no longer read, and have difficulty reading my email. Even labels on food products, reading a shopping list, or a traffic sign are now often difficult. And even watching TV is now becoming difficult after a while.... A week ago I went to a doctor to check out stomach pain that I was experiencing, and I got sick just from filling out the intake forms. On top of it all, Aetna, my disability insurance company, has decided to cut me off.., because I am not considered disabled under their guidelines...I need to sue, but given my condition, it will make me more sick...so it's like a catch 22.

My mail goes unread, and my to do list keeps growing and growing..

Also, I found out this month that my mother had a malignant tumor in her intestines, and had to be hospitalized for a few weeks. She will need to undergo chemotherapy. She also fell and has two

fractures and is hospitalized. In my given state I can't do anything to help...

March 2003 - Present

Went to the Mayo Clinic. Am very impressed with their expertise, attitude, thoroughness, and way of doing things; definitely the best practice of Western Medicine I have seen anywhere.

After a week long of diagnostics, where pretty much all doctors are quite baffled at this condition, (even the head of psychiatry, who keeps pushing to look for a medical condition), I see a bright "**behavior neurologist**" who diagnoses my condition as a "**conversion disorder**" (a rare condition caused by prolonged and severe stress where some people go blind, others get paralyzed, and yet others lose speech) causing mutism and cognitive impairment. I greatly identify with this diagnosis. The solution suggested is to do **Cognitive Behavior Therapy (CBT)** which they believe will restore a great deal of my functionality after very long and hard work, although they don't believe I could ever be a software engineer again. However, the prerequisite to CBT, is the absolute avoidance of stress...Also, no suggestions are given on how to avoid relapses.

Some suggestions are made as to how to preserve mental energy. With this in mind, I am very excited at knowing that there is a way out, and I set back home to implement this protocol.

By doing some of my exercises, I was able to gain some speech, and more brain power.

But strong relapses, and their resulting ear infections, along with fatigue and weak immune system, take me back, thereby canceling any progress made, and regressing further. At this point I believe that the Mayo diagnosis is correct but partial, and that given the relapses, **CFIDS** is still a major factor...Also, the avoidance of stress, especially for me, seems impossible given daily responsibilities, and therefore the CBT process seems impractical. Still, I believe, a major gain in function can be gained by CBT if only given a proper chance...This probably means a prolonged leave from any responsibilities, and complete focus on CBT, and general improvement of health.

It should be noted that the Mayo Clinic at this time does **not** believe in CFS or CFIDS.

In addition, Mayo found a borderline high cholesterol level, as well as an elevated bilirubin level (liver panel) which they think is a probable **Gilbert Syndrome**, but nothing in terms of a health issue whatsoever.

July 04

Established a definite link between **detox and nutrition** to brain power, thereby also proving that the Mayo Clinic was partially correct at best.

Saw a healer, Tracy Jones, highly recommended and published, with whom I spent a whole month working hard on his regimen from early morning till bedtime.

The regimen included intense detoxification (SPECIFY), and a nutrition program (SPECIFY).

Within 3 days, I felt like I have not felt before in years.. Energy/vitality had improved dramatically, and I was able to speak almost at normal volume, for about 20 minutes a day. Afterwards at home, I was able to maintain that routine for a few months, and doing well, speaking about 20 minutes a day.

However relapses would still be triggered the same way as before, and because the routine took up about 6hrs/day, I let go of it. It felt like I was functioning on "super unleaded gas", but did not quite fix the engine...It's also quite clear that I'm quite "dirty" inside" (lots of bugs, worms, parasites etc.), and much of the food does not get digested.

CBT at Harborview - no success

Tried MVVT

Looking into Electrical sensitivity; there is definitely something there..

Neurofeedback

RELAPSES DESCRIBED

The physical part I call a 'relapse', or 'imbalance' or 'out of whackness', or 'flare'. I can't fully explain the subjective feeling that I experience when this happens, but I'll do the best I can. All I can say is, that it is horribly debilitating to say the least. This has gone on since 85, when I experienced a sudden decrease in brain power, but in '96 I completely lost the ability to speak.

The main ingredient of that relapse is a **gradual yet quick decrease in brain power**, (**JUICE** is the operative word here as it disappears quickly) the **ability to focus and process, visualize**, and **'normal' awareness of my present** (surroundings, context of whatever I am doing etc.).

The already low brain processing power is weakened even more.

This is similar to car battery that loses juice quickly and recharges very slowly. Every action drains juice (like turning on head lights, listening to the radio, turning on the AC etc.) When they're turned on simultaneously juice drains much faster. A relapse is when all juice is gone, and the car runs on empty, causing internal damage to the system.

The side effects are **severe internal weakening**, **weakening of the immune system**, **openness to colds** during the relapse and more. I don't remember it all, I need to go check my writing.

I also **lose the minimal speaking ability** that I do have (in the AM, that's prior to 4/02 when I could speak a little sometimes). I also feel a **lack of oxygen**, I need to close my eyes and breathe a lot to clear and focus my mind.

It takes anywhere from a couple of days to a few weeks to heal from a relapse depending on circumstances (i.e, how strong is the relapse, how strong am I prior to the relapse). This is experienced as a physical (NOT emotional) immobilization. I "know" inside and feel, that this relapse is extremely detrimental to my health, so I do the best I can to avoid it, but am often unsuccessful, as it is very hard to control thought, and interaction. Depression and frustration occur naturally as a result of a relapse.

Another way to describe the feeling is , that I am already operating on a depleted scarcely filled cup (with energy/vitality), with a broken wall down its length (i.e a vessel with a leak). I can't fill it because of the break in the wall, and when a relapse happens , the remaining fluid leaks out completely leaving the cup empty, and dangerous to operate in such a condition. I never know if the cup will refill...

The triggers are thought for a given duration (about anything, say I play chess for a while, which I love, or read something analytical, or think about something sad , it's all the same), speech about anything to anybody, even laughter, and lack of sleep. I have had to quit many chess games in the middle when I felt a relapse approaching. Another way to cause a mini relapse is a 'sudden move'; e.g: I'll play chess, and see a great move, and say to myself, "aha gotcha" (to the opponent that is). This is a sudden release, and will cause a relapse. Laughter, as well as a sudden move such as a kick or a punch where I need sudden focus falls into this category as well. This is very hard, because I often forget, and laugh, and then hit a mini relapse.

During a relapse, I can barely function and unable to do simple daily tasks without difficulty (cooking, cleaning, pay a bill, check a bank deposit or whatever you do on a normal basis)

There is a huge amount of emotional pain., sadness, accumulated over the duration of this condition. Most significant perhaps is the loss of time (17 yrs). Life is 'on hold' and I have little ability to deal

with issues. I try live each day without relapsing. Like walking on eggshells.

the healing process from a relapse is slow; it may take from a few days to months to build up to the point before the relapse. e.g: in 1/01 I had a bad relapse and ear infection as a result(the worst ear infection my doctor has ever seen.. or so he said, but both ear drums, and was in excruciating pain). it took me more than 8 months to start learning a little again, and play some chess....

“disconnect” in leverage

short circuit

burned fuse

loss of flavors of awareness

loss of mind power, severely weakened

severe loss of chi and general weakness, felt in head and mouth/tongue area

very weakened immune system- will catch anything, ear infections etc.

WHAT I EXPERIENCE DURING AN "IMBALANCE"

- a "gap" in the present moment; i.e the present goes out of focus. I am barely aware of surroundings or my own body.
- Consequent loss of clarity.
- physically "wounded" feeling of the mind
- gaps in memory; i.e after the gap in the present moment, it takes time to come back to the point where I was before it started, and pick up from there.
- loss of certain mental functions like visual thinking and visualization, absorbing of information, even simple things like watching TV or reading
- severe drain of energy, very weakening, fatigue.
- tingling in certain parts of the body, like lower back and heart areas, and tongue.
- susceptibility to colds (or whatever happens to be there at the moment)
Difficulty in healing e.g: took me more than two weeks to heal from a wisdom tooth extraction.
- lack of air, need to breathe a lot to clear the mind

TRIGGERS

"interactive focus":

- Primarily speaking; (before february of 1996, I could still speak ok for about 30-40 minutes, after which I 'd get to the point where continuing speaking would cause an imbalance).
- too much focus on the person I interact with, usually I notice an imbalance after the fact; e.g I like to joke around, so when the person is joking with me or vice versa, I may incur a similar imbalance.

Prolonged thought:

- Usually of a concentrative kind; e.g: I'll study literature on something heavy and all of a sudden I'll notice that I went too far, and incurred an imbalance. But also, thoughts of a non concentrative kind, if they are repetitive for too long a period. Also sad thoughts.

Lack of sleep.

Operating on lack of sleep, especially things that require concentration

DURATION

Anywhere from a few days to a few months (depending on current physical strength, severity of the "hit" and quality of the care). Usually need to sit and do nothing for a while immediately after an imbalance.

Often times I feel a great urge to eat after a relapse.

EXAMPLES OF ERRATIC MIND/BRAIN FUNCTION
And Relapse triggers

For definition of “relapse see attached sheet

Prior to April-Oct 2002)

- speech about anything will immediately incur a relapse. I stopped speaking in 2/96. I can whisper on a “good” day for a few minutes.
- read any document for over 15-20 minutes, depending on how much analysis is needed, will cause a relapse.
- deep thought of anything.
- a chess game after about 15 minutes. I stopped playing, evn though this was one of my favorite things.

As of April-OCt 2002, the following cause relapses (Basically the same phenomenon, but with much less reserves of brain power)

- Read anything for a few mintes. Even a shopping list, or ingredients on product labels.
- Think of anything for a frew minutes.
- Watch TV for about 15 minutes.

Simultaneous thinking processes will cause relapses very quickly such as:

- Driving, changing lanes, and changing radio channels simultaneously.
- Driving and thinking of anything simultaneously.
- recently, driving and listening to music simultaneously.
- Parallel thinking, i.e thinking of several things simultaneously.

A “sudden move”, like being attacked and the need to block, or anything where I need a real time reaction and a burst of quick awareness. examples - Martial arts , q quick driving reaction, etc.

Speed Processing, like reading a menu, and trying to get a quick impression of what’s available.

Following a conversation, even when not being part of it