

**Chapter 4, Wanting in to the Garden of Healing**

“Where there is no imagination there is no horror.” *Arthur Conan Doyle*

**Healing is a fenced garden. You walk around the outside, look for a way in.**

Dr. Dixon-Warren pointed out to me that part of my back pain came from the muscles in my upper back going into spasm. Gradually, I learned to differentiate this pain from the pain in lower back, which was in the sacro-iliac joints. I came to understand muscle spasms were self-inflicted, so to speak. I became worried, and as a result so tense, my muscles just knotted. The word spasm is originally from the Greek *spasmos*, from *span* to draw, pull. It's defined as “an involuntary and abnormal muscular contraction.” I wonder now that my GP didn't just give me muscle relaxants. What happened was I learned to control the muscle spasms. It was not as simple as just telling myself *Smarten up and fly right*, a favourite phrase of Mum's. After some trial and error, I learned to first address the fear. There was nothing wrong with my upper back. The spasms were panic, pure and simple. As close as I can put it, what I did after that was relax into allrightness. And then I relaxed again and again, each time yielding more, until my back muscles unclenched and the pain stopped.

But nothing helped the pain in my sacroiliac joints. After months of tests, no one had a clue what was wrong with me, let alone how to fix it. “I'm just a GP,” Dr. Dixon-Warren said. “If your family feels they'd like to get more specialized medical help, that's fine. Your mother-in-law is talking about Scripps Diagnostic Clinic in California, I understand.”

I understood my doctor was a nice man. I was embarrassed to hear him humbly say the things about himself that my family had been saying. I mumbled something placatory and fled

from my usual three week appointment. At that point I'd been hospitalized for two weeks, and had extensive physiotherapy. The rheumatologist I'd been referred to said, "You're strong as a horse from the waist up." The neurologist said, "There's not much wrong with you." The allergist (married) told me I was allergic to my Siamese and suggested the two of us get together out of office hours.

Pearl, my mother-in-law, had found out that Scripps Diagnostic Clinic was just as good as Mayo, as well as a lot closer to home. Once she learned that, she felt it was obviously right she send me there as she was related to the Scripps family, the Scripps Institute of Oceanography, etc.

Pearl loved the idea of rescuing people. She was always lending her tenants drapes, and then fretting when the thoughtless souls cut up her good fabric and made something else out of them. Or else she'd leave behind valuable sherry glasses when she rented a house furnished with antiques, and was surprised when her renters broke her glasses. "How could anyone break fourteen cut glass sherry glasses?" she asked me once in amazement. "In one year? They seemed so nice. He teaches at UBC, you know. I think it was that sister of his."

My mother-in-law was also generous, always trying to give Jamie and me things: vacations in Fiji, couches from a great stash of second-hand ones she'd come by, wood-burning stoves, whatever she felt the need was. With me, she decided the need was better medical care.

Scripps Clinic was large and blindingly white in the California sun. Inside, the atmosphere was hushed and religious, with fountains, green plants and a vaulted ceiling studded with tiny diamond-shaped skylights. At Scripps, the head of the Pain Clinic, Dr. Richard

Sternbach, asked me, “Aren’t you angry?” A blond man with a soup-strainer moustache, he spoke very slowly and appeared sorrowful. I liked him a lot.

I was surprised by his question. I hadn’t said a word to him about Jamie: whatever the doctor had picked up came from the pain questionnaire which lay on the desk in front of him. I looked at the blue ink of my upside-down answers. “Why should I be?”

“Most people would be in your position. Your husband is not exactly, hmm, supportive.”

He wasn’t? He said he was. So I wasn’t the only person who didn’t believe him? What a relief. I focused back on the man in front of me. “I feel hurt.”

“Yes?”

“Well, I accept him with all his quirks. He’s not perfect. I just don’t know why he can’t accept me. Even when I’m in all this pain, I’m still me.”

“Most people would be angry,” Dr. Sternbach repeated.

I shrugged. The air-conditioning in his office made it downright frigid; I would have preferred the heat of the California sun. I crossed both arms. Under my hands, the sleeves of my pretty new cord jacket were soft. It was burgundy, my favourite colour. Outside the window *scheffleras* grew, their leaves like beautiful green-fingered hands. I had a *schefflera* at home, but it was an indoor plant in a pot. Those ones were foundation plantings; they were ten feet tall. The old name for them was *brassias*, but that had been superseded. What a wealth of useless lore I carried around with me.

“On a scale of one to ten, with ten being the worst, how bad is your pain right now?”

I thought of the horrible drive into Vancouver when the pain spiked me almost out of my seat. That’d be a nine and a half right there. I drummed my fingers on the arm of my wheelchair, rented for this trip. Even though I felt my eyes half-closing with the ache in my back, I thought I

was a long way from the most pain it was possible for me to bear. Soon I'd be finished at the Clinic for the day, and I could go lie down. I was a commercial fisher; I was tough. How much pain could I take? "On a scale of one to ten, what's it now? Three."

***Blaamp, wrong answer!***

I didn't realize until years later that the correct answer to *How much pain are you in right now?* was the one Vietnam vets who worked with Dr. Sternbach gave: six out of ten. I came across the answer in an article he'd written. Chronic pain patients with less than a six were dilettantes in the world of pain. Mere triflers. I tapped my fingers on the page and thought about it. Six? I could see the reasonableness. But it didn't matter. There was nothing in the diagnosis or treatment that would have changed with the right answer. Only my embarrassment.

Meanwhile, back at the temple, Dr. Sternbach gave me a neurostimulator. The neurostimulator had two plastic pads which I moistened with gel and stuck on with thick tape. These went on over each sacro-iliac joint. The pads were connected with wires to a tiny battery operated transmitter which hooked over my belt like a pager. When I turned the neurostimulator on, a trickle of electricity flowed through the wires to the pads and to my sore joints. That produced a prickling effect. When it was turned up too high, it hurt. I was supposed to keep it just so I could feel it pulsing. The idea was similar to the application of heat: it was a counter-irritation which didn't stop the pain but distracted from it, so in effect, a person felt it less.

"According to the hmm, pain questionnaire you filled out," Dr. Sternbach said, "I am led to believe you have a strained sacro-iliac."

"I do?"

“Hmm, yes. It’s a classic case.”

After all this time of having a back problem with no name, I was boggled and delighted to be a classic case of anything. It didn’t even sound too dire. “Will I get better?”

“Providing you are careful not to re-injure your back, and you do your exercises, yes.”

“When?” I demand.

“Will it be better? In a period of hmm, some months to a year. I must caution you, however, that it might take years to completely heal, and it will likely always be a weak spot.”

I read the booklet that Dr. Sternbach gave me. It was helpful. This was where I first ran into mention of the Vietnam vets who were in chronic pain. I learned that instead of waiting until the pain got too intense, I should manage it and take my pain pills at regular intervals. I was not supposed to call them pain *killers*. The medical profession winced at that terminology. By taking pain pills every four hours, I’d use less and my pain would be under better control.

Dr. Philip Hench was the next expert I was sent to. He was so well-known as a rheumatologist I would later find his name cited in books in my local library. Dr. Hench, a thin pleasant man with a dry sense of humour, had no less than thirteen certificates on his walls. He’d won a scholarship to Mayo, done post-grad work there, won awards of merit and the like. Outside his office at Scripp’s, hibiscus bloomed, red-flowered, as tall as a person.

Dr. Hench told me two new items of information. The first was that I had a heart murmur. “Nothing to be concerned about, it’s just the blood making a noise as it goes round. Millions of people have them. The thing is,” he tapped his stethoscope with his finger, face alight with interest, “yours is a particular kind. It’s often associated with ankylosing spondylitis.”

The second thing that Dr. Hench told me was that I had a genetic tracer in my blood for ankylosing spondylitis, the HLA B27 antigen. “But it’s a very unusual disease for a woman to

get,” he said. “It’s sex-linked. Men are the ones who get it. So it seems improbable that’s what you’re actually dealing with.

“This kind of arthritis is associated with two others,” Dr. Hench said. “We don’t know why. But until you develop uveitis, an inflammation of the eyes, or colitis, which is an ulcerative condition of the bowels, we won’t be persuaded that ankylosing spondylitis is really what you have. What you have at the moment is an elevated sed rate that indicates inflammation, but who knows why? It could be a number of different reasons. So far you show none of the degenerative changes in your spine associated with ankylosing spondylitis.” Dr. Hench smiled benignly. “Though time has a way of making these things clear.”

I looked up ankylosing spondylitis when I got home. In a layperson’s terms, it was spinal arthritis. It was called bamboo spine because all the vertebrae in your back fused. Unless a person took particular care to exercise, they ended up with shoulders bent and rounded, head poking out. It’s disfiguring, distinctive. Once I knew what I was looking for, I could spot a man with ankylosing spondylitis half a block away.

What I came home from Scripps with were those bits of knowledge, a series of exercises to do each morning, a delicate suggestion that I might be making the problem worse than it really was—my pain level of three wasn’t consistent with the disability I was experiencing—a booklet on how to control pain, and a black neurostimulator to hang on my belt, its *tick ticking* of electricity pulsing through my skin and into the sensitive joints beneath.

### **The zinger.**

Oh, and a final comment from Dr. Hench about my back problem that was different from Dr. Sternbach’s. Dr. Hench said, “Learn to live with it.”

In your notebook:

- 1.) List the ways that well-meaning people have suggested to you that you learn to live with your problems. Is this something you've said to yourself?
- 2.) Write down what would you give to get rid of your problem(s). Have you ever heard someone saying I'd give my left/right hand to .... fill in the blanks? Or I'd give my left/right nut? Front teeth? What would you give?

Fairly extreme but it beats suicide, right?

- 3.) After you've done this, write a paragraph in response to the question, *Do you see the extent to which you have allowed problems have become your touchstone, so to speak?*
- 4.) Write a paragraph in response to the following statement: There is a creative consciousness which is right now creating our universe of infinite potential. I am included in this abundant, joyous universe.