

# **A Year Out of this World**

**Illness as a Teacher**

**By Nikki Basuk**

**For Jack, Jerry and Steve**

**"Je vois la vie en rose..."**

There are many voyages in life, until the final destination. Most people will not know the manner or time of their death.

Welcomed, a life-threatening disease can become a powerful teacher.

Mrs. B. is a writer of fiction. At work on her novel "*Wrath*," she is stricken suddenly with a rare, aggressive, autoimmune disease.

This book chronicles how she comes to embrace illness as a teacher of life.

# A Year Out of this World

## Illness as a Teacher

### Out of nowhere

She ached. She sighed and closed the computer. She was not sure she liked how the work was progressing. The prologue may be too aggressive, she thought. She was not sure about the first scene. The Ann character needed more attention. It was hard to remain focussed. The pain was different from the one she was used to. It was clawing at her flesh day and night. It haunted her dreams. She was not sleeping. She kept waking up every time she moved. She was not taking well to this new drug. She had started taking it after osteoporosis was diagnosed in her hips. Perhaps she should stop the drug. What were the choices though? She was slim, agile, faithful to her Tai Chi morning regimen. She watched her food. What else could she do that she was not doing already? It was late. She had been immobile too long. She stretched and willed herself up. A hot bath, that was her next step; her problems vanished often in the steam of the bath.

"Jack," she called out. "I'm in the bath."

Tillie the toy poodle came running, anticipating her usual fight to the death with the discarded clothes. The water ran clear. Her mind wandered. Why was she hurting so? She looked at herself in the mirror. Nothing showed. She lowered herself in the water. "I'm going to take it easy," she thought. "Perhaps we should go away somewhere." She woke up with a start. How could she have fallen asleep in her bath? That was not like her. She got out and toweled herself hurriedly.

"Tillie, come here, I have to brush your teeth."

In bed, she stretched out against her husband's back. He was warm, comforting. She snuggled. "I'm going to dream of Blanche and Constance," she thought. "That's bound to make me feel better." She had taught herself to dream stories she would write upon awakening. She could go back to them in her sleep at will. For the past few weeks, she had been experimenting with a special love story.

## Too Much Reality

The pain had colonized her. It was everywhere in command. Every move brought its own exquisite torture. The room was dark still. The luminous dial of the clock showed six o'clock. Jack and Tillie snored softly. She closed her eyes and tried to get back into the dream. Blanche, Constance...She had to get up.

She stumbled and nearly cried out. She groped for her slippers and robe and went out of the room softly. Things were not right. Her ankles were badly swollen. She hurt in every joint and muscle abominably. The skin behind her knees was tight and sore. Her calves throbbed. "I'm a mess," she thought. "Perhaps if I eat breakfast..."

Back at her computer, she tried to concentrate on the story. The pain was like a pointed hook jabbing at her. She would write nothing good today. She closed the computer.

"Tai Chi?" she thought. She put on the Bach CD and began the warm-up movements. Slowly, she moved up into the cloud of the stretch and cried out. The agony had come upon her so sharply she nearly fainted. "Perhaps I should go back to bed. No. I'll take a bath."

She walked back into the bathroom. How could she have missed it earlier?

One eye was badly swollen and drooped. The left side of her face was puffed up as well. It was time to call for help.

## **Eyes**

The ophthalmologist said, "A biopsy of the tear gland is needed to rule out certain scenarios, like a tumour. Can you be ready in two days to have it done?"

It was early in the morning. A light November rain was falling. The waiting room of the hospital was painted a cruel yellow. A few people were already waiting. They looked at her and looked away. Each was locked in private pain.

"Mrs. B.?" The nurse waved her into a small white room. A bed, a few instruments, a window looking out into the yards of the hospital. She shivered.

"So how are we doing today?" The doctor entered, followed closely by another nurse.

"Lie down, please, and don't move your head. This should take about 15 minutes. And we'll have the results quite soon. Don't worry about a thing."

The needle was a spear bound for her left eye. An icy hand gripped her heart. What if...It was too late for what if's.

She was back at the ophthalmologist's office. Her left eye drooped even more. The pain in her temple drove out everything else. It merged with the pain in the rest of her body and insulated her from the world. She was pinned in her cocoon of pain.

"And how are we today? I have the results from the biopsy. The good news is, you don't have a tumour. The bad news is, I don't know what you have. I'm arranging for you to see another ophthalmologist in Vancouver. He's a specialist's specialist, an ocular oncologist. Not that I think you have cancer. I'm sure he'll help you. Don't worry."

The paper with the name and number was in her hand. She walked out, numb. What could be the matter with her? It was time to stop dancing around in distress. She would take her life back.

The Vancouver receptionist was expecting her call.

"Mrs. B.? Can you be here at 2:00 p.m. tomorrow? Yes? We'll see you then."

She had never had such a thorough eye examination before.

"We'll need to do another biopsy. It will be a bit tricky because of the earlier biopsy but possible. Are you staying in town? Let me see. I could do it tomorrow morning. We have surgical rooms right here."

She was back the next day. She was shown into the small operating room. It was cold.

"Ah Mrs. B. The procedure will take about 20 to 30 minutes. We'll inject a local anaesthetic. If you feel any discomfort at all, tell me right away. Once we start, you must not move your head at all. No matter what, do not move your head. Do you understand? Are you ready?"

The spear needle zoomed towards her eye again. She tried not to blink, willed herself into immobility, thought herself into a pebble. Time stretched. She felt the jab.

"Pain," She said. Her voice came out funny.

"Hold still," said the surgeon. The spear came at her again. She felt it enter. There was no pain, just the shape of the movement into her flesh. The doctor was chatting amiably with the nurse. She heard them from a distance. She longed to close her eyes.

"We're done. You were excellent. Very composed. Very helpful."

The nurse placed a bandage over her eye.

"You'll be shown how to care for the wound. And I'll call you as soon as we have the results from the biopsy."

She did not hear the other nurse's words.

"Do you have the instructions in writing?" she asked.

Sheet of paper in her hand, she walked out to the area where her husband was waiting. Tillie scratched madly at the net of the soft kennel resting on the chair next to him. They walked out of the building together. Her head hurt.

They were back home. It was late. She knew she could not continue to be borne by events, helpless. She had to take control again.

"Jack, whom do we know in the medical community? We have to start calling around. I need a top GP to start with."

"I'll make some phone calls tomorrow. Why don't you take a bath and go to bed?"

The next day was spent on the phone. At the end of the day, she had an appointment with a doctor in Vancouver. She was going to get to the bottom of her problem and deal with it. Methodically. So she could get on with her life.

The day after that was a Friday. At 2:00 p.m., the phone rang.

"Mrs. B.? This is Dr. Redding. Please listen carefully."

### **Sentence**

Wegener's Granulomatosis. WG for short. More intimate that way. What kind of a name was that for a disease? It did not sound real. What on earth did he mean, "serious, immediate treatment, good chance of survival,

remission possible?" It was not cancer. So how serious could it be? He had insisted, she was to call his office right away for an emergency appointment. She dialed.

"Mrs. B.? Yes, Dr. Redding will see you on Monday at 1:00 p.m. Please make arrangements to stay over in Vancouver, just in case you are referred to another specialist. I'm sorry, I can't tell you any more, the doctor will clarify on Monday when he sees you."

She opened the computer. She accessed a medical database and punched in the name of the disease. For the next two hours, she sat immobile, absorbing the dreadful details. It was the end of her life as she had known it.

*Wegener's Granulomatosis, WG to the aware, is a rare, aggressive, necrotizing autoimmune disease, an inflammation of the blood vessels. It can start in any part of the body. Left untreated, it could travel to any and all the internal organs. It is difficult to diagnose. Many patients die of it undiagnosed, death believed to have been caused by other means. Until more*

potent treatments were discovered, death from this disease could occur within five months from diagnosis. Usually, WG starts in the sinuses or in the lungs, in only 30% of cases in the eyes. About twenty years ago, it was discovered that a combination of chemotherapy and steroids could induce remission of up to five years and more in many cases.

Monday, 3:00 p.m. for her 2:00 p.m. appointment. She was back at the oncologist's.

"Mrs. B., don't be alarmed. This is a serious disease. However, I believe you are at the beginning of its manifestation. It is not systemic yet. At present, it is localized in your eyes. Treated immediately, there is no reason to believe that complete remission cannot be induced. I would like to get you started immediately on cytoxan and prednisone."

"What about the side effects? They sound as bad as the disease. How certain are you that I have this WG? Where would it come from?"

The doctor became visibly impatient.

"Look here, Mrs. B., I see many such cases. Those that get treatment go into remission. Those that don't..."

"Wait a minute, Doctor. How many patients are you currently treating?"

"About twenty."

"And how many of those are in remission? And if so, for how long?"

"Let me give you a copy of a paper of mine that was just published. It will give you more precise information. Now, I urge you to get treatment now, not to wait. The longer you wait, the less your chances are of halting this disease where it is now, local, before it starts to migrate."

"Doctor, I need to think about this."

"There is nothing to think about. You need treatment. The most effective one is the one I have recommended."

"I still want to think about it."

"Very well. In the meantime, I suggest you start on antibiotics. This is not a treatment that has proven to be effective, I must tell you. But until you make up your mind, it may buy you a little time. I have arranged for you to see Dr. Mersham. He is a rheumatologist. In this case, he'll be the body systems man. And I understand you have an appointment with Dr. Lainier. A GP is a good addition to the team that looks after you."

She went out, clutching the prescription in her hand. What was she to do? The doctor's paper pictured twenty or so horrors, patients, some of them children, in such a state of disfigurement and pain she had trouble identifying with them. True, she avoided mirrors these days. These folks had subscribed to various treatments. Some to the sulfa drugs she may take. Some to the combination the doctor had advised. Yet some to other drugs. And one had refused treatment altogether. That one ended up in the emergency ward of a hospital and died soon after of kidney failure. The message was chilling but clear. The one treatment that gave patients the best chance was the combo. No treatment was death.

Another day, another doctor. The *GP* was a friendly, comfortable man. He had a stellar reputation in medical circles. She liked him immediately. He talked to, not at or past her.

"We'll need blood tests," he said.

"What are you looking for?"

"I want to see how well your thyroid is performing."

She was to become increasingly familiar with the technicians who mined her veins twice monthly, looked at her under X-rays, drove the *MRI* machines.

She was back in the *GP's* office.

"I don't know how you get out of bed in the morning," he said. "Your thyroid is functioning at such a low rate, you should have no energy at all."

Lack of energy had never been one of her problems. Whatever life threw at her, she attacked with all her being.

"So what's to be done about it?" she asked.

"You'll have to take replacement thyroid hormones for the rest of your life. Just think of it as food supplement. Start with this dosage. I'll see you in two weeks."

One week later, she was back at the ocular oncologist's. Her arms were adorned with the red pinpoints of an angry rash.

"You must stop the medication immediately," he said. "You are allergic to sulfa drugs."

"What now?"

"The only choice we have is the combination we talked about earlier. There is nothing else."

"I need some more time to decide."

"Decide soon. Your X-rays show no sign of WG elsewhere in your body so far. Neither does the MRI. Yet your blood tests show elevated inflammation. You may not have the time you think you do."

Three hours to get to Vancouver. Three hours to get back to Victoria. The weekly trip was becoming unwanted routine. Jack was not even bothering to be seasick anymore. And Tillie hated it just as much, but more quietly. Mrs. B. remained in the car during the entire journey, to keep the pooch company. She brought along food, drink, books, pillows. The trip was interminable.

What should she do? The treatment was meant to suppress the immune system, hoping to calm the disease along with it. The side effects were harsh: no defense at all against germs, viruses and bacteria; loss of hair; nausea and diarrhea; fatigue; risk of bladder cancer; osteoporosis; and more. The steroids would deform and swell her face to a moon-like shape, having melted down her muscle mass and deposited fat along the way.

The pain overwhelmed her. She lived in intimate closeness with it. It governed her life entirely. It was present in her every action, her every

move. Nights came and went, unslept. Days came and went, unfelt. The pain was a being inside her own. She would never be alone anymore. She had not written a word in days. She paced at night and roamed the Net by day. She searched for explanations, recourse and remedies in all the medical libraries she could access. So much data. So little knowledge. There seemed to be no way out. She needed a second opinion.

Five or so weeks later, she received a response. "...In our opinion, you do not have systemic Wegener's Granulomatosis. However, the lesion may represent an idiopathic sclerosing inflammatory pseudo-tumour of the orbit. Lesions of this type may be associated with a systemic immunologic disorder. A localized form of *WG* may be present..."

"Clear as mud," she thought to herself. "No doubt the doctors will agree at my autopsy that I died of something." She could not decide what to do. She had asked all the experts she could think of. *WG* was such a rare disease that even going to the Mayo Clinic may not bring better results. Her problem remained whole: should she start aggressive treatment now, should she wait?

Morning. She washed her face. Her eyes hurt. She glanced at the mirror. Her heart froze. Her right eye was swollen and drooped. "At least they both match", she thought. How could this happen? November, one eye droops. January, the other one droops. In between, endless hours spent waiting for doctors, meeting doctors, calling doctors, reading doctors' reports, her flesh pricked for blood, her innards photographed too often, the interminable ferry crossings, the Vancouver rush hour traffic, her life a band-aid. All right. None of that sorry and why useless stuff. The future was now. The disease was on the march. The doctor was right. She had less time than she thought.

"I don't think you have systemic WG," said the rheumatologist."

"You don't? Then..."

"Oh, I don't mean there is nothing the matter with you. I think you have a connective tissue disease that must be treated."

"Treated, how?"

"Prednisone, for a start."

The rest of his words became a buzz in her ears. Back to full circle. There was no escape from the drugs.

The ocular oncologist looked deep into her eyes again.

"No question, the left lacrimal gland is dead. The right one is badly impaired but still active. There is inflammation in both eyes. You must start treatment now. Let me give you the prescriptions. The druggist will give you precise instructions on how to take the medicines. How much do you weigh? The drugs are calibrated according to weight. Can you arrange with my receptionist for monthly visits? And please call me immediately if anything, anything at all worries you. The drugs will make you vulnerable to infections. Therefore, if you catch cold, call me. If you don't feel well, don't wait, call me."

She left the office and cut herself in two. One Mrs. B. took the prescriptions, arranged for the visits, repeated the doctor's words to Jack,

walked Tillie around, got into the car en route for the ferry. One Mrs. B. retreated into her mind, pondering her future. Was the whole effort worthwhile? Did she want to live anchored to existence by a chemical bond? The treatment was to last one year. The disease was chronic. It could never be cured. It could only be put to sleep. With luck. Or not. All her life, she would be looking over her shoulder for WG to strike at her again. That is, if she survived long enough. Was survival now all there was to living? Her father had died of mini strokes inch by inch, over a five year period. She had sworn to herself she would never end up like he did. Was now the time to put herself to the test?

Safe inside her mind, she screamed and wailed. She was caught, bound and gagged. She was to be melted in a crucible she did not understand, shut down to be re-initialized. Her tried and true life weapons had been torn down all at once. If the disease did not put a mask on her, the drugs would. If she lived, that is. How could she let it happen, passive, hoping the treatment would work. just to live a little longer? "I can't," she cried inside her head. "I can't step aside and pretend to be brave. I'm scared, I'm so scared. How can I go by fragments, in dread, defenseless, without a fight,

since I can't even see the enemy! I'd rather die! Too soon, though. Too soon to kill myself. I have to think about it some more. There must be something else I can do." Her eyes were closed. "Now I can't even cry," she thought. "No tear glands to cry with. That will come in handy when I peel onions."

"Nikki, are you asleep?" Jack was shaking her. "We're almost there. How do you feel?"

"Well," she said.

She thought about nothing else for the next few days. She wanted to live and she wanted to die. She was immobilized into non-action.

Winds of rage so powerful flailed at her. Black cloaks of despair hugged her, leaden as a mummy. Useless questions and useless answers clogged her brain. Everywhere she searched for a way out. Every time, she was pushed back into the waiting arms of her fate. Miserable days followed sleepless nights. She spent her time glued to her computer screen. The Internet offered no miracle. Pain had become a second skin.

Through it all, she washed clothes and prepared meals. She must have spoken too, because sometimes she heard Jack respond to her. Her feelings were sealed inside her. None escaped. She was a walking tomb.

Bit by bit, amidst the seeming chaos inside her, her next step was taking form.

### **The ultimate freedom**

Even before she really faced her decision, she began the work of erasing her presence from the home. She gathered all she had not used in the years before. Papers, personal mementos, clothes not worn every day, were thrown out or given away. Files were brought up-to-date. Family pictures were neatly arranged in albums. She prepared memos to Jack outlining where important documents were stored, how to care for Tillie, when to visit lawyers, doctors and investment advisors. Important telephone numbers and addresses were added. She amended the blueprint of a living will she had requested earlier

from her son the lawyer. She had it witnessed and sent copies to her lawyer and her banker. She reviewed the will drawn years before.

Her thinking had crystallized finally. For days now, she had been working so that Jack would have a house clear of her things after her death. In action before thought, she had made up her mind. She would not live in the shadows, shackled by an implacable disease. She would die free, by her own hand.

She had always had the means to kill herself. That was her ultimate freedom. It was the price of choice. If life became unbearable ever, she would deal with it her own way, she had always thought. That day had come.

She had not told her sons that she was ill. She had not shared with Jack the unfolding of her thinking. Her plans remained deeply sealed within her mind. She felt nothing.

For a few days she pondered the logistics of suicide. To have Jack rush her to the hospital if he came home too soon would wreck her planning. She

needed a large block of time to herself. Most Fridays after tennis, Jack went out for lunch with friends. He was gone for four or five hours. She would kill herself on a Friday. Two weeks hence.

She sat down to write three good-bye letters. The first two to her sons were long. She had to explain in details why she had chosen to die. She found it difficult to squeeze into phrases the love she felt for them and meaningful last words. She was exhausted. She put the notes away and thought "I'll read them over tomorrow. Perhaps I can improve on what I wrote."

She read them over the next day and found she could add little. No matter what she said, she could not shield them from the pain she would cause. She set out to write her letter to Jack.

Sitting down at the kitchen table, pen in hand, she started to tremble uncontrollably. Sobs without tears, sobs from a place deep in her belly, sobs shook her and left her weak. Jack. They had met in mid-life. They were each other's second chance at life. They loved each other so.

Burial. She had forgotten about burial. Did she need to leave instructions?

No. Jack and her had discussed this many times before, never thinking the need was near. He knew she would want a traditional burial. For her sons. For him too.

Her mind wandered. What did she know of the mechanics of death? Two faces came unbidden to her mind. Elle, their beloved collie. Her friend, defiant to the end.

Elle died in my arms that day, she remembered. The vet placed her on the table and prepared the injection. She rested her nose on her cast and waited. Hospital routines had become familiar to her. I embraced her. Elle put her head on my shoulder, the needle entered, and Elle died. She went as she had lived, gently. One second she was a living, breathing being. Then she was not. The memory of her body is imprinted in my arms still, she thought, with a terrible sadness for the fragility of life.

And her friend...She could not bear thinking of that morning.

She had slept badly the night before, she recalled. This was not supposed to be, she thought. We had plans. We were going to play at growing old, my new old friend, my kin.

The other three women met me inside the funeral home. They were friendly in a subdued way. It was early in the morning. They had prepared the dead together many times. They were easy with each other.

"Have you done this before?"

"No," I replied.

They explained in detail, as they donned white lab coats and rubber gloves.

"You may do as much or as little as you are comfortable with. You may find this difficult. It is a good thing you are doing."

We went in. The room felt small, bathed in artificial lights. A shape shrouded in a blue blanket crested the slab adjacent to one of the sinks. Pails and towels had been arranged. On another table, snowy clothes and a bag of earth from Israel were carefully laid out.

I felt like a hand just grasped my throat. From the depths of me, a lake of unshed tears rose unbidden, swollen with all the times I had not cried. I fought and pushed it back firmly. "Not now."

There was little talk. The women went about their chore, competent, earnest, a team. I felt as one with them.

She was washed. First her head. How heavy death. As we lifted her to cleanse every part of her body, her head nestled in my arms. She burrowed into me. "Hide me, save me..." I hugged her. I tried. I could not hide her. How to save her... She insisted with the weight of her body. It seemed to me that her entire weight was concentrated in her head. So heavy.

Her blood coloured her back and legs. The war against the disease showed through every bruise, puncture, old bandages and caked blood. It had not been an easy fight. She was cold. So cold. I washed her back. At the base of her spine, there was a square bandage. I started to remove it. Her skin was so thin that I feared it might tear. Two of us pushed on the skin while I

pulled at the bandage. A vile stench rose from the punched hole that was hidden. Where is my friend? I steeled myself against the smell. I could not escape it. I shut off all feelings, all sensations. The bandage came away. I washed the wound. I moved down to her private parts. No modesty in death. Nowhere to hide. No escape.

As we turned and washed her, I felt anew the weight of her death in my arms. My body retained a memory of her shape, of the daintiness of her feet, of the slender shape of her fingers. I do not have to think about it. My arms are still cradling her head as I gathered her unto me.

The women were silent except for words of instruction murmured kindly. "All together, turn, hold, turn, put her down, there is a drop of water in the corner of her eye, slip the head rest under her head."

There was humour even in death. My friend's big toes were red with polish. All attempts at removing it failed. One of the women went out in search of stronger solvents. "Dust to dust..." The nail polish disappeared. Her nails

were clipped, the clippings carefully gathered. They belonged to her, even in death.

She lay naked upon the slab. We lowered her so that the slab drained into the sink. One after the other, three pails of water washed over her from head to toe.

Carefully, almost tenderly, she was dried and dressed in the white clothes of death. The bonnet softened the anger on her face. Not for her a peaceful surrender to her fate. She took her place in the simple coffin that would house her in the cemetery. Jewish earth was sprinkled upon her. The lid was fastened. The coffin was draped, black cloth upon it with a single white Star of David. It was over.

We shed our white coverings and gloves. One of the women hugged me.

Tears sprung fast to my eyes. "Will you stay with her a while?" I nodded yes.

I held the tears till we were alone, my friend and I.

The coffin stood before me. The small waiting room was empty. "Now," I thought, "Now." I reached in to tap the inner lake of unshed tears. I could not find it. I could not cry. The moment had passed. Only anger remained, anger that passed over me like a wave. To tame the rage, I began the ritual of meditation. After a while, I was able to empty myself of all feelings, and to concentrate upon the breath going in, going out. A friend walked in. I could not believe that nearly an hour had passed. I was calmer. I gathered my things and went home.

Mrs. B. shook her head to clear away the images conjured up by the thought of the disposal of her remains. That was not her concern. Jack would have to see to that. Folks familiar with the rituals of a traditional burial would help him out and comfort him.

Sitting down at the kitchen table, pen in hand, she tried again to write her good-bye letter to Jack. The room blurred and contours softened. In the next instant, her world shifted. Had she been religious, she would have recognized a vision.

She saw a road, stretching long before her. She felt the truth of the road in her bones. It was the road of her life. She had allowed the course of it to be determined early on by the needs of people who held no love for her, her parents, siblings. They had fed at her strength and at her willingness to be used by them. Ever hungry for their affection never shown, she had lived her young years governed by a misplaced sense of duty. She had allowed no room for dreams, for pleasure, for feelings, for expectations, for the wild in her. She had carried the burdens of their living instead because she thought her folks were weak and needed her. Even as a girl, she had fought their fights. She had not glimpsed other ways. Yet the more she had given them, the more they had resented her. She should have run away from home at the earliest opportunity.

She saw that as an adult, in her relentless struggle to claw her way out of poverty towards financial independence, she had become stuck in a one-track life strategy. She had lived her entire life embattled in survival mode. The financial pressures exacted by her parents and the responsibility of bringing up her two sons had consolidated her binary worldview: the world is a battlefield in which you are either victorious or dead.

She understood now that along the way, her immune system had tried many times to call her attention to the personal toll exacted. She had ignored every warning, determined not to give in ever to the body's weaknesses. Now her system was giving her the ultimate warning. You did not listen, now you die. She saw that the road was leading her to the logical conclusion of how she had lived her life. Having let others determine early on the kind of life she would lead, she was walking their road taking her to her death.

Then she saw that she did not have to stay on that road of her life. She could choose to take another road. All she had to do was to get off and step elsewhere. She took a breath. Could it be that easy? Her fate was in her hands. She could always kill herself should she choose to. She may not have to right now, however. She could start building her own road and live. It would not be easy. It would demand all the determination and courage she could muster. Living would have to become her life's work. Living well, not existing, that is. She took another breath. She stepped off the road of her old life onto another road. In the beginning....She felt reborn. The room was

bathed in radiance. She returned to the table in her kitchen, pen in hand.

Tillie came near to lick her hand.

She phoned her doctors and scheduled another round of visits. The fight was on.

### **The fight is on**

The visits to the doctors had been exhausting. She was to see them once a month for the next year. She dreaded the treatment, a combination of cortico-steroids and oral chemotherapy. A half-hour with her pharmacist had confirmed her worst apprehensions. The side effects of the drugs would be harsh.

She had been a control person. Uncomfortable in a chaotic universe, she had always established order quickly upon her personal and professional environments. She ruled herself with an iron hand. She looked upon the ordeal of the treatment as just another hurdle to master. Will, hard work and courage. That would pull her through, now that she was going to live.

In the fight against the disease, she would need allies. She went back to the Internet in search of support groups. How were they coping? What additional information could they supply? She was surprised to see that the WG group was international. And linked to other sites. A number of participants had been part of the group for fifteen, seventeen years. That was good news. Many had become experts on their and other autoimmune diseases. The survival rate when treated was encouraging.

She lurked for a while then waded in with a list of questions. She wanted to know everything these people did to help themselves and the treatment. She took note of all the supplements they were taking. She was impressed by the group's willingness to answer her. Their warmth touched her. Through them, she became acquainted with the problems that lay in wait around her corner: sleeplessness, mood swings, pain, loss of hair, weight gain, moon face. In time, she would become discouraged by the endless messages cluttering her e-mailbox. After a suitable period, she left the group, grateful for their support and knowledge while she was connected to them. She was a loner, even on the Internet.

She still had not told her children she was ill.

She was on the phone with Steve. She had always been grateful for the close bond between her and her sons. They cared for each other and communicated well. Her son was speaking. She was making appropriate sounds, she thought. They rang off.

This could not go on. In time, her sons would feel how remote she had become. She was in fact betraying their relationship. Jack had warned her. He had been entreating her to be forthright with them. She just could not bring herself to do it. After all, was freedom from her not the best gift she could bestow on her sons? She had always wanted them to be free to go their own way, unencumbered by concerns about her. How could she tell them she was seriously ill? Yet how could she not? Their conversations would become stilted and artificial, just like the one she had shared with Steve tonight. She would be unable to carry on as though nothing had happened.

She called Steve back.

"Do you have some free time? There is something I want to talk to you about and I need about an hour of your time. Call me when you are free."

Her son's voice was strained.

"Anything wrong?"

"Well, is now a good time to talk?"

"Yes, yes, what is it?"

"Well, I have some news I'd like to share with you."

For the next half-hour, she proceeded to walk her son through the past few months. She held nothing back. She spelled the name of the disease, she explained the treatment and the hopeful remission rate. She took extra care not to let any emotion cloud her tale. She wanted to be factual, clear, rational, truthful.

"Steve?"

"Yes, I'm here. It's a bit much to absorb. How do you feel now? Are you in pain?"

They agreed that they would speak again the next day. When her son called her back, he knew all about WG. He had researched it carefully and was conversant with symptoms and treatment.

"Did you tell my brother yet?"

"Not yet. I'm calling him tonight."

"Well, when you do, I suggest you not start by telling him that you need an hour of his time and then proceed with the cold facts. You nearly frightened me to death! Try telling him you have not felt well for a while. It sounds more human and may give him some time to adapt to the idea that you're ill."

She had thought carefully about how to approach her sons. Obviously, there was no easy way to deliver bad news. She called Jerry.

After the back and forth of "how are you's," she asked him whether she could share some news with him. She would need about an hour...

For the next few days, her sons called every day. They each had their own bit of research to add to her growing cache of information. They were very worried. That she was a stressful factor in their lives at the moment angered her. They were trying to make their way in the world. They should not have to worry about her in addition, she thought. In time, she reverted to her habit of asking much about them and speaking little about herself.

Now her days were punctuated by the intake of medicines. Mornings, afternoons, evenings, bedtimes were but reminders to take pills. The twelve cups of water made mandatory by the drugs were difficult to ingest. She would not be able to stray too far from home for a while.

For the next year, she would have no control over her body. Diarrhea stalked her. She took to wearing absorbent protection. Mornings were spent adjusting to the waves of nausea and dizziness that possessed her head.

Unpredictable pains traveled over her. Her skin thinned to the point that any encounter with any angular object left bruises or cuts that would not heal. A blob of fat colonized the corner of her left eye.

For the rest of her life, her bathroom routine would include scrubbing her eyelids with a Q-tip dipped in baby shampoo and irrigating her eyes with artificial tears three or four times a day.

She had once prided herself upon having a youthful body, kept taut from all those years of Tai Chi. Now the drugs melted her flesh and reshaped her skinny. She lost eight pounds in the first two weeks, even though she was aware that most WG patients tended to gain much weight.

She turned away from mirrors. The long white lock to one side, stylish hairdo of her previous life, was cut short haphazardly. It was limp and dull. Handfuls fell out when she shampooed. Gone were the artifices of healthier times, mascara, lipstick. One day she was young and the next she looked old. She became invisible to herself and others. Never beautiful, she had known how to cast her female message so men responded and sought her out. Now it was of no importance. It belonged to an earlier, trivial past. Now that each

day may be her last, she wanted meaning, not attention. She was an outsider to existence, between and betwixt, outside looking in, a stranger to herself too. Once upon a time under the illusion she was free, now she felt shackled by formidable bonds that neither wishes nor tears would dissolve.

She followed instructions to the letter. She avoided contact with people suffering from colds. She rested. She washed her hands endlessly. She researched her problem for hours on end, till she thought one more bit of information would drive her mad.

Every day, she went out for a walk. How she felt was not an issue. Fresh air and some exercise were a must. She knew every public bathroom on her path.

She enlisted every aspect of her life in her search for life. She had never been keen on eating. Cooking had always been an obligatory chore. Since Jack loved to eat, she had become a better cook with the years. Now food was medicine.

She put together for herself an anthology of useful food. She endlessly researched the positive properties of common and unusual ingredients. Garlic, ginger and onions haunted her cooking. No morsel crossed her lips that was not endowed with purpose. She ate to live. Jack would look at some of her concoctions and swear he would die first before he ate what she did. He maintained that she was torturing herself with food unfit for any civilized palate. He argued she was making herself sicker by the look and smell of the strange stuffs on her plate. Undeterred, she ate on. Understanding Jack's objections and his attachment to more regular fare, she would cook two-tier meals most times, his and hers kind of meals.

The game plan was, she would take the cortico-steroid and the oral chemotherapy at suitably high dosage for a number of months. Then if she seemed to be doing well, the drugs would be reduced gradually. If everything fell into line, it would take six months more to get off the drugs completely.

The months were punctuated by regular blood tests. She sank or hoped by the light of lab results. When the doctors were too worried, the tests were repeated.

The days passed. Then she started to cough. A little cough at first. Then a high fever. She stayed in bed, drank cup after cup of hot anything, slept more. After a week of no improvement, she called her doctors. They were stern. "Any complication could be grave," they said. She should have alerted them immediately. X-rays were ambiguous. She did not know what the doctors were looking for. She had a bad cold, what was the fuss. The doctors prescribed antibiotics. She got no better.

During the following week-end, the week-end of hell, her Vancouver GP and his office set up a sort of relay arrangement. "You get any worse, you go to the hospital," were her marching orders. She called them faithfully every few hours. Somehow, it was Monday morning again.

Her next Vancouver visit revealed that she had had a bad bout of pneumonia. Until then, she had not really felt fragile. True, she was sick from the medicines, but then she was expecting to be. Therefore she could cope. Dangerous infection was another matter. She had no defense against it. She

could be ambushed at any time by a stray bug. And her efforts to hang on to life would come to naught. She had to revisit her whole approach.

### **A life-long teacher**

Rethinking her predicament, she realized how little she had learnt from it. Although she understood intellectually that she may have driven her immune system to extremes because of her "in your face" stress-filled approach to life, she was in battle mode still. Her very vocabulary betrayed this. She was locked into a "fight" with the disease; she was "fighting for her life;" the drugs she took were "the only available weapons at the present time." Her parlance was peppered with the tactical words of her previous life: "face the enemy, attack, stand your ground, always bully a bully back, remain alert at all times, have courage..."

WG was not a curable disease. At best it could be put to sleep. Fighting it head-on was a self-defeating strategy. She would have to change herself and her life in more fundamental ways if she hoped to survive.

After days of reflecting upon what to do, the answer came to her. Simple. Not easy, but simple. The disease had been the most fundamental agent of change in her life so far. It had wrestled out of her hand all familiar coping tools. She was naked and vulnerable before it. Putting out all the energy she could muster to "fight" would only boomerang, causing her greater harm. The harder she fought, the harder she would be struck. She had to learn to use the disease's momentum, and follow where it was leading. She needed to turn her life and herself around completely and forever. In a spirit of humility and respect, of gratitude for showing her the way, of reverence before the life force, she would adopt the disease as her life-long teacher. This would become her life's commitment.

It turned out to be more work than she had bargained for.

First things first. A complete inventory of all possible means of getting back to health was in order. In Vancouver, a top team of specialists working in concert looked after her. In Victoria, two emergency physicians were on stand-by. She read up on WG constantly. She could think of no improvement

she could make on the conventional side of her treatment. Except one: avoiding people, germ-carrying people, colonies of microbes on two legs.

From that time on, she retreated into solitude. Every day, she got dressed and went out with Tillie, often with Jack too. They walked and walked. She saw nobody. She did not speak to anyone if she could help it. Her neighbours were greeted politely, from afar. Groceries were delivered following her telephone orders. Jack did the bread and vegetable buying. If she had to go someplace frequented by humans, she donned a surgical mask. She wore white cotton gloves that she replaced and washed every day. The technicians at the medical laboratory got used to her twice-monthly, then monthly veiled presence.

There had to be more she could do to help herself. What about the complementary side of medicine? Once or twice perhaps in all her years of Tai Chi practice she had experienced a floating, a flying, a liberation so intense that she strove ever to recapture it, in vain. No amount of discipline, of hard work would bring forth this sensation she had experienced too

briefly. She did not understand what brought it about, nor why she could not recall it at will. She had resigned herself to its whimsical nature.

Many books later, she realized that she had been approaching Tai Chi wrongly, as gymnastics, as work, more work. The mechanics of her movements were part of her larger problems. She thought about it some more.

In time, she would try a number of meditation techniques, chanting, relaxation through music, dance and controlled breathing. She never stopped her Tai Chi routine.

Eventually, her Tai Chi style underwent an utter transformation. She learnt to combine breathing with the cadence of slow form. One daily set lasted almost an hour now. She strove for never more than the flow of the moment. Her balance grew, with it her confidence in her ability to get her mind out of the way. Once in a while, she lived a moment of intense awareness.

She had hit upon what would be the focus of her efforts for the year. For any or all of these remedies to have a chance at inducing a remission of the

disease, she would have to quiet somehow her ever-questing, critical mind. She would have to quell her natural tendency to analyze and take apart. She would have to grow a large virtual broom in her mind. That broom image became the first one she woke to and the last one she used before she fell asleep. With her broom, she swept away the negativity of each day. She stopped reading newspapers. She never listened to the news. She seldom answered the telephone. She concentrated on getting her mind out of the way.

## **Hypnotherapy**

Hypnotherapy seemed one approach that book after book recommended in cases of autoimmunity. First she laughed at the idea. She did not think she could be readily hypnotized. Then she decided to try it anyway. She made a few phone calls to get the name of a reputable hypnotherapist, one that did not bend spoons. She made an appointment with Dr. Hobbs.

Early on a Saturday morning, having ascertained that the good doctor did not suffer from any cold at the moment, she sat on the comfortable armchair facing him.

Dr. Hobbs had asked her to send him a letter describing her reasons for seeking relief prior to the visit.

"To: Dr. Hobbs

From: B.

I am looking forward to meeting you. As agreed, here are an explanatory note, a brief medical history and a fact sheet on the disease. Please do not hesitate to call if I can provide anything else you may deem useful.

Last November, I was diagnosed with a rare autoimmune disease called Wegener's Granulomatosis. In my case, it is not systemic, but localized in the eyes. In other words, I was lucky that it was caught at a very early stage. In fact, as these diseases go, the diagnosis is never firm or clear. It

does not matter, because the treatment is the same, immunosuppressive therapy with steroids.

How stress is handled is a major factor. If I had only known then what I know now...I was a very tense, very action-oriented, very dedicated high achiever. I was a fierce believer in 'where there is a will, particularly of course my will, and there are many ways.' I took every blow square on the chin, because I could take it. A Cartesian through and through, both by culture and temperament. Such arrogance....

I can see now how my body had been trying to warn me for many years that I would have to change my ways. In the past 10 years or so, I experienced a variety of arthritic and sundry problems, diagnosed under various labels. I ignored it all, because I have a high tolerance level for pain and because one is not a sissy, is one? After all, who is the boss, me or this body? And now I have this mental image of my immune system jumping up and down, trying to get my attention, and finally turning upon itself in despair, much like a dog begins to chew on its own fur.

After wrestling with the fears and implications of WG, I began to see what a gift it really was. It turned my life around. I stretched and changed in ways I would never have dreamt of not so long ago.

There are no other stresses in my life. I have let go of all those. I am trying to live in the present.

I would like to work upon a visualization of a non-linear representation of time/space/health. Also, I have this image in my mind of my ghostly immune system I try to talk to and soothe out of its fears and agitation.

I have always mediated the world through intellect. This year, I am trying to reach for spirit and appetite. Not much experience at it yet, but with your help...

Thank you."

The good doctor reassured her that no matter what, nothing would happen against her will. Hypnotherapy etc...etc...Mrs. B's mind wandered. She knew all that. The books she had read stressed the very same things. She stifled

a yawn. The doctor stopped talking and asked her where she wanted to go from there.

"Techniques. I need to be taught techniques to reach my inner mind. The rest I know."

A bit flustered, the doctor asked her to lean back in her chair, to close her eyes and to imagine a beach, with a house on the beach. She was asked to get closer to it in her mind, to open the door, to walk in. She was encouraged to step down the set of imaginary stairs, to approach the safe in the wall, to open it and to place into it all her earthly burdens. Then light and free, she was asked to walk into the room where she would meet the ghost that would tell her...

She started to laugh.

"Doctor dear, the ghost I've just met in my mind is an old crone who wants to know why I am paying you \$125 an hour for such nonsense. This is not going to work. I'll tell you what. Why don't you lend me a few books? I'll read them

and come back. Then we can try what I'm more comfortable with. How about it?"

He did not seem to resent the situation. He suggested they try another technique, then he would lend her books and try it her way.

She sat back into her chair. The second technique, meant to put her in a trance, did not succeed any better. The doctor had made a tape of it, which he handed to her.

"Why don't you practice with it every day at the same time? Then call me whenever you are ready to go further."

She agreed.

A few days later, she decided it was time to get in touch with her inner mind. Right then. She looped a key ring to the end of a piece of string. She sat upright at the kitchen table, her elbow resting comfortably on the surface, holding the string up and free. From the books, she had gleaned the "connect with your inner mind" correct parlance.

She stilled herself. Silently, she asked "My inner mind, will you talk to me? Move left if yes. Move right if no. Move up if you don't know. Move down if you can't tell me."

She breathed slowly and quietly. She was absolutely still. The room was silent. The pendulum started to move. It rose. It rose left. She freaked. She shook so violently that she dropped the string.

To: Dr. Hobbs

From: B.

Re: Update

Hi Dr. Hobbs.

Thank you for loaning me "The Symptom Path to Enlightenment." I am endlessly fascinated by the birth of a new way of describing human reality. The book merits notice if only by its attempt at fitting the language of the new sciences into its realm. While I support the new language, I can't forget

the admonitions of friends who are mathematicians. They say that this new language is meaningless since it attempts to translate mathematical equations into imperfect and vague thus incorrect concepts. Nevertheless, since words shape our reality, a new way of describing it can only be welcome. It is my hope that it will open new ways of being heretofore not accessible.

Speaking of accessing...after my stunning pendulum feat, I have been at it faithfully every day, with complete lack of success. I have tried various methods, signals, entreaties, with total indifference as a result. Perhaps I should stop my new custom of spitting at the pendulum when I see it?

I have been using your tape every day at the same time, 7:30 p.m. It has been working very well. I can relax my muscles at will, a skill I had learnt when I was pregnant and had forgotten about. I seem to either relax very deeply or fall asleep in the middle of it however, and come back up when I hear you start counting from 10 to 1.

Please let me know whether you have other books to suggest or lend me. I will call your office for an appointment after the summer. Perhaps you can make me another tape with a different method at that time.

Thank you and be well."

The doctor never returned her phone calls. Falling asleep was not an acceptable result of hypnotherapy.

The drugs held her mind in a grip. She was plowed over by rages so powerful she shook sometimes. At other moments, she plunged headlong into vats of gloom. She minded how she walked, how she turned, because she was dizzy always. She held onto life by a thread of sanity.

Her routine helped. Besides keeping house as best she could, all her daily self-assigned prescriptions kept her busy. She added dancing to the lot, for her spirit.

She read endlessly. She ordered books from the library via her computer.

Jack picked them up and returned them. Zen, stories about people who survived grave illnesses, paths to enlightenment any which way, voyages from the mind, advice from the wise, advice from the not-so-wise, poetry, history, mysteries, words marched into her head and went out again.

Almost every evening, Jack would put on a movie. Her selection criteria were simple. The movies had to be upbeat, excellent, non-violent. Jack the movie freak came through every time. This way she could be alone but with him.

Eventually, she returned to her tried and true coping technique. She went away emotionally. It was the only way she could resist the overwhelming mood swings. No longer would she have to worry about keeping the lid on herself not to turn Jack's life into hell. She functioned reasonably well on automatic.

The only glimpse she would allow into her soul she gave to M., who lived elsewhere and had become her closest friend. Once, she told M. of her becoming so detached.

**Excerpts from Mrs. B.'s e-mail messages to M.**

To: M.

From: Nikki

Re: musings

"I live a strange life, on two tracks. In one, I answer the telephone, I do my chores, I speak to Jack, I have conversations with my children, I walk outside. I go on with the business of life, but I am quite detached from it. Actually, distancing myself from the needs of others has become easy. Lately I have been obliging myself to speak to Jack a little more, because words align themselves less freely in my mouth. Moreover, I like to talk less and less. I am sure nobody notices the difference, but I listen more than I used to. In the other track, I am completely alone. Alone in a way that I, the consummate inner loner, have not experienced before. Alone with feelings, efforts, fears, small victories and setbacks I can share with no one. In that track, I live in silence, inside my head.

I try to put my mind aside. I try to let go of purpose, of action. Sometimes I feel I understand what it means. Most times I know I have exchanged one effort for another. I speak in my mind. I brush away negativity. I hold this big virtual broom and sweep away with energy at the hostile thoughts that peep in constantly. Rosy is the colour I strive for. If only the world would oblige. I experiment with meditation in many forms. None is easy. Every time I think I have reached the way, it is gone. Oh, to be at peace with myself and the universe....

I pursue relaxation relentlessly. Except when I catch myself at it, not often enough. Then I can relax truly. For an instant. I strive to live in the moment, that is, to be conscious of the moment. It is easy to fall into the trap of nothingness, I have found. What is difficult is to hold one's mind open, yet not mired into irrelevancy and routine. To be aware of the unique moment in time, not to fall asleep with one's eyes open. It is so difficult. I start the Tai Chi movement meditation, and find myself mentally gathering the wandering threads of my thoughts, again and again. Or else I know my mind is blank but I am not in the moment, I am not at once detached and aware.

Besides the set, I have started more esoteric forms of Tai Chi meditation. One calls for assuming a position that mimics sitting on a horse: legs wide apart, sort of half squatting, body straight, arms rounded at shoulder height as though holding a large balloon. The meditation time is fifteen minutes. So far, I have endured six. Try it, you'll see what I mean!

I monitor my body on a constant basis. It is not a truly conscious act, you understand. It is more like an automatic sweep, a low-level kind of check, which brings itself to my attention only if something is not right.

I speak to my body. I entreat it to cooperate, to be strong, to be cured. I move with a constant purpose: does this add to wellness or not? I am putting all of my efforts in my mind-body connection. I have fashioned a list of facts I hope will come true in the near future. To forge new and positive neural connections, I recite them to myself morning and night and more. I work on breathing, on standing, on moving, on being. I recreate myself every day. Mind you, I am much less frantic about it than say four months ago.

To my eyes, I don't even look the same. True, now that I have been taking below 7 mg of cortisone for about three months, I have lost the round puffiness that transformed my face. And my voice has returned to normal. But. My left eye is smaller than the right one. There is a little pouch in its corner. I can slice onions with no problem. No tears, you see. I have deep bags etched under the eyes. My hair is cropped short and very thin. There are wrinkles where firm flesh used to be. My muscles have melted and my bones need caring. The doctors tell me that despite my best discipline, the muscle mass will never really come back. I don't believe it. They don't practice Tai Chi, what do they know about muscles? How can I stand for minutes on end on one foot if I don't have muscles? Strangely, I am indifferent to all this. Funny. Once I was so conscious of my appearance, so careful of my stage effect.

I have developed a sort of family relationship with my Vancouver team of doctors. Dr. Redding has been diagnosed with rheumatoid arthritis. We both share in his concern for his future. Dr. Mersham is the team coordinator. From his office flow the results of all my tests to the other four doctors. For him, I keep the records of my blood work myself, plot it and distribute

the results regularly to the three doctors. Dr. Lainier is a wonderful man. I love him. He is committed, bright and kind. He is patient with my endless questions and research tidbits. The six of us and the lab technicians are stretched on an endless information spiral, linked in time/space by phone, fax and computer memory.

I am at the centre of my world. I know this luxury, this single-minded attention can't last. I try and enjoy it while it does. I have not known this before. I may not know it again with such intensity. Perhaps I can find who I really am before it all goes away. You called me a monk. I look forward to reading the articles you sent so I can understand what it means. Sometimes I think it would be wonderful to be able to spend time in a monastery, with no interruption, no responsibilities and no chores to do.

Why am I sending you this long selfish navel-gazing letter? Well, whom else am I going to send it to? Who else is interested in my current state of affairs? And to whom would I send an honest no-frill self-portrait?

Big hugs

Nikki"

To: "M.

From: Nikki

Subject: musings

Hi. I'm still laughing. I love to see myself through your eyes. What a hoot.

I even delayed my Tai Chi session to get to the computer. I knew you'd be back at me.

Monking is a great word. The gerund implies one has a choice. You can start monking around, and then when you tire of it or want to do something else, you turn to 'doing' it. Having become a monk is a different process. Having turned into a lemon precludes my having become a banana...Fromm notwithstanding.

At the same time I like the monk notion, because it brings forth such an

amusing archetype, although my meaning is very far from having adopted a new

role. The transformation is so much deeper. It is as though I had lived in a world without the colour green. Then I am able to see green (is it not fortuitous that I did not choose red as an example) and it changes me and my world completely.

Have no fear, I have not turned into a saint, how could I? And I am not a convert either. It is just so very difficult to convey what happened to me without sounding pompous, obscure, faddish or self-righteous. I've never been introspective and my mind is not nimble like yours. Thus I find myself in very strange territory, with no map and no lantern. All I can say is that something happened to me, something that has changed me forever, even if I seem the same to my friends.

Strange how people read you, or rather do not, even people close to you. At the height of my drugged state, I felt that the old god prednisone had taken possession of my very soul. I was racked by uncontrollable rages, possessed

by anger and despair the depth of which would scorch me. What to do? I knew the mood swings were drug-induced. That did not make them easier to handle. So instead of fighting, I went away. Literally. I went about my chores and whatever I had to do, but I was not there in mind and spirit. I came back only to meditate and do these things that I felt would strengthen. After I had stopped the drugs, I asked Jack whether he thought I was moody or edgy during the past year. He said he could not see any difference in behaviour. He is so used to my being controlled and even-tempered, and he was so scared for me all the time that he disengaged from seeing anything that would lead him to believe I was not well. He thinks that if I have changed at all it is because I am better physically. And I would not try and dissuade him. Or perhaps I have this all wrong and he is trying valiantly to shield me from his own emotions. Have I succeeded in muddying muddy waters? What a relief I don't share these musings with anyone but you. It takes a true friend to sit through it all

and remain on writing terms with me! I promise I'll be more fun soon!

If I had your kind of insight and analytical abilities, I would understand everything much better.

Be well,

Nikki"

### **Living not living**

The drugs peaked and then she started to decrease the dosage. Slowly. Very slowly, not to re-awaken old man *WG*, assuming he was asleep.

She understood drug addiction. Every time she lessened her intake of prednisone, her body rebelled violently. For a week, she shook uncontrollably, was swept away by dizzy spells, endured excruciating headaches and pains in

her joints. She felt cold. Sometimes she vomited, sometimes not. Getting off the drugs took six months.

For too long, she saw her Vancouver doctors too often. Eventually she graduated to monthly visits, then sessions every two, then three months.

All during the year, she was distracted by strange and inescapable dreams, drug seeded, remembered in vivid details. She took to writing them down in the morning. As she read them later, she could see how she was working through the disease's messages in her sleep. The metaphors and images were transparent sometimes and other times not. Unwilling to shake the pendulum again, her immune system had found another path to her.

### **Excerpts from Mrs. B.'s Dream Diary**

August

I had taken some time off for thinking on a beach. I had taken wine in a basket. Tillie pranced along, the sky was clear blue, pebbles were white on the shore. Nobody in sight. Suddenly, a large dog materialized out of nowhere. I panicked. Tillie was calm. The dog came near, licked Tillie's nose. She licked his. I heard him speak in my mind.

"Love me. Love brings forth the speaking ability in all animals. We forget if we don't exercise it. Tillie is very bright. She keeps her speech channels open by the strength of your love for her. Think of how often you tell her 'I love you Tillie.' This has kept her speech skills alive all these years. Humans knew this then forgot and now they can't communicate.

You will have a happy life, a happy old age and you will die peacefully in your sleep. You will make a real impact upon the world. 'Wrath' will be very successful, as will the books that follow. You will help because your idea is right: the brotherhood of man. You must expand it to the brotherhood of all beings.

You knew I would come. One day, your message got through to me. You had kept it to yourself all these years. You knew I would come when you called me. Remember."

He placed his huge head upon my shoulder. I held his large body. "I love you," I said. "I love you," he breathed and died. I felt a light enter my soul. It is time, brotherhood.

August

I am sitting at the dining room table. Whoosh...From far, I see myself sitting. I am in a tunnel. At the mouth of it, dimly seen, shimmering figures hover.

A voice speaks low:

"You are cured."

"Cured. Then I can stop drugs and treatments?"

"No, you need the discipline. Continue as planned. But remember, you are cured. Now. When enough time has passed, you will embark upon the project of your life. How will you know what it is? You will know. The world needs repair. Remember, when you decide it is time for you to go, we will be here waiting for you. We love you."

I was back at the dining room table.

I could share my absence with no one.

October

In court. No people. No seats. A parquet floor.

The judge asks me whether I can dance. The music starts. "When they begin,

the..."

I dance. I sing. The judge asks me whether I had noticed the minister sitting there. I had not.

A "Man of God," living in a comfortable cave open to the sea and the rising sun. Just in front, railroad tracks and noisy trains. I ask him how he can bear the noise and soot. He says:

"You can ignore the bad when your eyes are fixed upon the good and the beautiful."

October

I am thinking how much I would like to stop the old god prednisone. Cold and snow envelop me. Suddenly, a man appears. Powerful, massive, not bad looking, with curly hair. He is wearing a sheepskin jacket, a hat, a flannel shirt.

I take him by the hand and lead him to a small street with inner courtyards accessible through a porte-cochere. One bears a sign reading: "Honorez les amoureux." French songs are playing softly. For the next hour, I bid him good-bye. He kisses me strong. I ask him about his youth. He had been a

veterinarian, then moved on to help people. We leave. Out in the open, I notice that he has forgotten his jacket and hat. I run to retrieve them.

A young woman asks me how long we had stayed.

"About five minutes," I say.

"More like an hour," she winks.

"Five minutes to some is like an hour to others," I reply.

I give the man his jacket and his hat. He leaves.

October

From a helicopter, I am watching the tall, slim woman wading in the river.

She is dressed in a light gray top and matching soft skirt swirling around her

legs. The river is wide, shallow and calm. The sun is shining bright in a blue sky tinged with white.

From the helicopter, I see that the river is feeding into a raging angry sea. The sea is throwing mad caps and spumes all about. I shout to the woman to get back. She can't hear me.

November

Many people are seated in our living room. I recognize some friends. Steve is helping me out. A complicated jungle of machinery is spread out the entire length of the room. At one end, a toaster; at the other, a TV screen. Steve pops the picture of a child into the toaster. I punch twenty minutes onto the VCR. After a few blips and burps, the TV screen lights up and shows the child as a grown-up. There are pictures of rocks, sea, sky, grandchildren, Steve and Jerry. The audience is restless.

December

The bones in my shoulders have been surgically removed and replaced by shoulder pads. Always in fashion now. It seems not to have been at my own behest. I demand that the surgeon explain why he did it and who ordered it done. I ask this from my hospital bed, lying down. There is no answer.

January

I am perched on a ladder, fixing up the cracks in the ancient house that is mine.

A messenger arrives. A relative has just died in Montreal. The funeral is at noon and the service at 7:00 p.m. It is now 4:00 p.m. Too late for the funeral, perhaps not for the service. I'll take the bus from Ottawa to Montreal. I glance out the window. The day is radiant.

I rush. I am ready to step out the door. A raging snowstorm takes my breath away. Three feet of snow have fallen in a few minutes. The whole city is still. I start out anyway, on foot, carrying my bag. After a few minutes, I can't tell where I am, where I have come from, where I am going.

April

I had gone to the chiropractor for relief of pain. He had me sit in a chair. He punctured both my eyes. "For your own good," he said. I could still see well, with two small holes where my eyes had been. Water and blood flowed through.

After a while, I found myself in a dry country, where an old friend lived.

After three days spent in a filthy hotel, I rang his doorbell.

He said his wife was out-of-town and showed me to my room. I told him I was a monk for life.

May

I pluck the long black hair on my leg. I pull and pull and pull. There seems to be no end to it. I feel as though my whole body were unraveling. After an audible "blop" sound, a feeling of closure. I throw the whole mess into a plastic bag and shut it tight. All at once, I experience a feeling of exhilaration, jubilation, passion, wild feelings with no names. My hair grows suddenly past my shoulders, curly and white. A beard and a moustache grow long and fall out, leaving my skin smooth. I hear my blood, my cells cry out "Free at last, we are free at last!"

**Stable**

By the end of December, she was drug free. She was also anemic. Her hair had thinned. Much of it had fallen out. She was pale. Her skin was translucent. She looked fragile. She tired easily.

She should have been elated. She was still alive. The harsh treatment seemed to have worked so far. She was off medicines. The blood work showed she was mending slowly. With care, her health would improve.

She felt no elation. Getting to where she was now had been the focus of her life for the past year. Instead of optimism and joy, she found depression. She could not shake it. She was crushed by the weight of sadness so profound she would never escape it.

Before *WG*, she would have kicked herself back into functioning. "Depression is for the weak," she would have told herself sternly. "Look at it in the eye, then get on with the job of living." Now she knew better. She waited it out. Day after day, she woke up to darkness in her soul and fell asleep with tearless tears. Then one day, things looked better. Little by little, she came out of the hole. Her strength improved. Her blood tests too.

After *May*, she could no longer remember her dreams.

That month, it came to her that she was going to live after all. She was progressing reasonably well. She had begun to go out in crowds without her surgical mask. "Communities of microbes" was still the picture forming in her mind whenever she came close to humans. And she would not relinquish her white cotton gloves. She was not rushing herself. In time, she would adapt. That month, she decided to forge her own calendar. This was her **Year One**, her beginning.

The condo they lived in had a beautiful view of the sea and mountains. No matter, she had come to hate that space where she had been so ill. If she were to live, it would have to be close to the sea.

Within three weeks, they had found a townhouse located a half a block from the greatest coastal walk in town, the condo had been sold, arrangements had been made to move on the first of June.

The townhouse was a modest affair on two floors; one of five on a quiet street. She adored it. It was perfect. A few renovations and colourful painting had transformed it into their space. A couple of times a day, she

would grab Tillie, go out the door and walk a half a block to the sea. It renewed her. Sunny, windy, warm, cold, wet or foggy, to her it was always wonderful. She belonged there.

She woke up in the morning grateful for her life and went to sleep at night grateful for her life.

On a fine day in October of Year One, the ocular oncologist looked deep in her eyes and said:

"No tear function whatsoever. Gone. But you're progressing very nicely. Clean."

The GP said:

"Stable. I'd like to see you next month to set out a monitoring roadmap. A visit every six months perhaps?"

Stable. The rosy shade of bliss.

"How are you?" her sons asked.

"I'm stable," she would reply.

"But how are you doing, how are you feeling, what do the doctors say, are you cured?" her sons asked.

"I'm stable," she would answer.

Stable. The most beautiful word in the English language.

She had many questions still, borne of her many months as a monk. What did it mean to live in the moment? How did one blend heart and reason to rally spontaneously in meeting the instant? How could aspirations and mistakes flow together to build life's road in walking it well? How did the mundane transform into the sacred?

She was beginning to sense that it would come to her, hopefully before time caught up and devoured her. The accumulated grime from all the years of false living had been pulverized away. If she continued to hold the now, quietly humble, centered and strong, she would find joy in every living blade of grass. The ideas she had struggled so hard to understand, non-grasping, non-action, awareness, detachment, could not be decoded intellectually, she saw that now. This new learning was by being, through embracing life as it unfolded. It would take time. Her new road beckoned, nourished with Jack's love, her sons' affection, Tillie's devotion and a few true friendships.

She had been melted in the crucible of her life, distilled to her essentials. She was without ambition, without regret, without future. She was as one with her disease teacher, in her now. She had come into her core.

She was that she was and she saw that it was good.

To: M.

From: B.

This is a curious period in my life, near the end of Year One. I want to try and describe it better before it melts away. It will. It's on too high a peak. I am completely at peace with myself and with the universe. I have no expectations. Not of myself. Not of others. I am in acceptance mode. Now you know it won't last, right?

Last year I felt old. Today I am. I am immobile in the flow. I feel eternity in the moment. I go for a walk and marvel at the beauty around me, the light, the sea, the sky, the sun, the clouds, the everyday. I speak to people from a great distance still, a true monk. They don't notice.

In Tai Chi, I marvel at the breath, the movement of my limbs, that I am able to do this at all.

I have gained a sense of the sacred, for which I have found a secure place in my heart. I walk with it all my waking hours. It has no name, no words, no shape. It is in me.

For as long as this lasts, I am deeply grateful. As I am for my life as it is today.

I know you understand."

## **A Minute**

I lived a lifetime inside a minute.

The sea came up and licked the shore.

Delicately.

The clouds perched on the shoulders of the mountains, waiting.

The sun traveled bright and went away to distant lands.

The air was blue around the edges.

It smelled of things too far and near.

The heron sculpted the horizon. Still.

The beak plunged and the fish thrashed caught in it.

Life and death violent intertwined.

Songs of songs poured from the throats of a thousand birds hidden in the trees.

The winds came up.

I lived a minute inside six dimensions.

## Epilogue

Mrs. B. crossed the street to the bookstore. In the window, "*Wrath*" was displayed boldly. "B.'s latest novel," read the banner.

She went in. She picked up a copy and leafed through pages at random.

Words leapt at her, moments of her life, frozen in print.

She put the book back and went to greet the owner. She was there to sign copies of her books.

"Good morning. How are you? What is your name? I'll be happy to sign your copy. And thank you, thank you so much."

## Autumn 2009

Once the immune system becomes impaired, it invites crowds of diseases and their cousins over for a party that lasts a lifetime.

I have been chronically ill for years now. I know that the underlying etiology, the

wounding of the immune system, has no known cause, no true understanding, no remedy as yet.

Proper diet, exercise, meditation, Tai Chi or any similar balance -oriented discipline, regular check-ups, thirst for learning and a resolve to live one's life

around passion and joy, not illness is the responsibility of every patient. I live my

life in the times in-between.

I have faith. We are mortal beings, that is our fate. Modern medicine will eventually however get us to our final hour in comfort, in compassion, in acceptance of our common essence.

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