



Jean Mallinson is the author of a book of short stories, *I Will Bring You Berries*, a book of poems, *Between Cup and Lip*, and with four other writers, a book of poems, *Quintet: Themes & Variations*.

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We read in folk tales about elixirs that course through one's body and effect transformations. Such elixirs exist to-day, one of them an antibiotic called gentamicin. Benign in its ability to hunt down and destroy pathogens, gentamicin in certain cases acts malignly to destroy the myriad hair follicles in the inner ear that enable us to stand upright, to place one foot in front of another. Those who suffer this toxic reaction are forever damaged, doomed to live in a shifting, visually unstable world, having to learn to walk again with a body that has lost its essential equilibrium, its inner steering device.

Terra Infirma - A Life Unbalanced tells the story of a summer that became a season of change through a toxic response to gentamicin and the author's struggle to reclaim a life in a body disabled by this modern elixir.

"Jean Mallinson, in her wrenching, compelling account of her own disability, reminds us that we, all of us -- wherever our station, whatever our circumstances -- live an uncertain, a wobbly life. A lovely mix of personal thought and literary quotation, Terra Infirma is full of honest feeling and whirling reflection."

Robert Hartwell Fiske, Editor, Vocabula Review.

Terra Infirma - A Life Unbalanced - Anna Jean Mallinson

Terra Infirma

A Life Unbalanced



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Terra Infirma

A Life Unbalanced



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*This book is for my children, for Lynn
Brown, founder of Wobblers Anonymous
and for all my fellow-wobblers.*

Damaged

The shambling creature
who has lurked in me since childhood
—the one who has no language but a bawl—
now lurches in my shoes,
stretches her legs in mine
weighs down my feet, trips me up
as I stagger
through a swaying world:

The landscape seems fractured
by a demented *animateur*
who makes the sky's plates shift
on one another, as trees, buildings,
the horizon, tilt like items
on a surrealist canvas,
and I myself am the lonely puppeteer
who dangles this shifting *tableau vivant*
from my peripatetic eyes.

Terra Infirma

A Life Unbalanced



Preface

I have written what neurologist Oliver Sacks calls a clinical fable—told from the subject’s, not the clinician’s point of view—about the destruction of my balance function by the antibiotic gentamicin. Though the events I record took place some sixteen years ago, I still live inside the constraints of this new way of perceiving and moving through the world. My diary focuses on how I learned to cope with this sudden, irreversible change in perception, locomotion and scope of living. My account is in part about what American poet Wallace Stevens calls “the imagination’s mercies”: the power of imagination, not to transform experience, but to give it meaning

In his book, *The Wounded Storyteller*, Arthur W. Frank speaks of ‘diagnostic shock’, and of what disability and illness do to desire (39). In my case, the shock of diagnosis, of being told that my condition was permanent, was tempered by relief that it was not life-threatening, and by the enlightenment of explanation. I quickly adjusted my desires to what was possible, and I continue to do so. In Frank’s terms I have written “a quest narrative, defined by the ill person’s belief that something is to be gained through the experience” (115). The impulse behind such a story is the need to render life meaningful. “Quest stories of illness,” Frank says, “imply that the teller has been given something by the

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experience, usually some insight that must be passed on to others” (118). Frank does not indulge in specious consolations: it would always be better not to be disabled. “Human illness,” he writes, “even when lived as a quest, always returns to mourning. The boon is gaining the ability to mourn not only for oneself, but for others” (136).

If there is anything unusual about my account, it lies in the rarity of my disability. Living without a balance function is a particular way of being in the world, one that I have never seen described in a book. My account is an attempt to make up for this lack. But if the rarity of my disability sets me apart from others, the normalcy of my response links me with them. No-one is safe, but our resources to live with and through a disability are shared and endless, as the oyster secretes its substance to turn grit into pearls.

Introduction

On a bright day in midsummer I stand at the curb edge of the lane behind my house, where the road drops a few inches to the main street, wondering if I can, without falling, lift one foot and place it down on the pavement in front of me. If I move closer to the side of the lane where I can hold on the projecting branches of the blackberry bushes, I might manage to stay upright while I carry out this difficult maneuver. But the pavement will not keep still, it rolls and heaves. I look up: the sky swirls, the houses across the street tilt and sway. My resolve collapses. My impulse is to get down on my hands and knees and crawl the few yards to the fence leading to the back garden of my house, but I cling to the bushes, open the gate and stagger up the garden through the lurching landscape, grab the railing of the stairs and pull myself up. Relieved to be indoors, with walls I can touch when I walk, I lie down, exhausted and discouraged.

My story tells how I came to this and how I learned to live with it.

Since my account turns into a matter of covering distances, how to get from here to there, I'll give a brief description of my location at the time. Divorced, I lived alone in a house

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in a residential neighbourhood built on the lower slopes of a mountain, on the Pacific coast of Canada. One of my two daughters and her husband lived in a suite at the garden level of my house. I have never driven a car. The streets of shops and other small businesses are at the bottom of a steep hill.

In late February of 1988, I had a spell of recurrent abdominal cramps. Usually after a few days on a liquid diet they went away. This time they did not, and I was eventually taken to the Emergency ward of our local hospital to undergo gastric surgery to untwist a twisted bowel. I was later told by my surgeon that I would have died without the surgery. After the operation and a brief stay in hospital, I felt a convalescent euphoria at having a chronic condition finally dealt with. Three weeks after surgery I was back commuting by bus to the community college where I taught English. My life of writing, teaching, looking after my house and garden, was normal again. I was well.

Then, toward the end of June, I began to experience again the abdominal cramps I thought my surgery had cured.

The Journal

June 26

 To my dismay, my old symptoms are recurring. They are familiar, from the attacks I had for years before I underwent surgery in March: intestinal cramps, slight but continuous. Anxiety. I thought the operation, a bare three months ago, had cured me.

I put myself on a liquid diet, and distract myself with reading, cleaning my house and planning a glass mosaic for the rain pool by the rock garden. I am reading *Under the Eye of the Clock*, by Christopher Nolan, an Irish boy with cerebral palsy, who, thanks to the faith and perseverance of his mother, is finally able to express his gift for language and his sense of his own life. Fate often brings me a book to get my life into perspective. His writing is fresh, as if he had just invented language. His list of blessings, to remind himself in anxious moods that he is, despite his disability, a sentient being, is deeply moving. Comparing himself to others in his condition before him he asks:

Did they ever delve their feet in cold water? Did someone ever feel for their clenched fists and gently prise them open, so that water could run between their

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withered fingers? Did they feel the cold nervous heartbeat of a damp frog? Did they hold a wiggling worm in the palm of their hand? Did they ever feel soft summer rain as it tickled down their face or the head bowed battle to breathe in the face of a blizzard? (19-20)

He says, and I agree, that none of us is what others see, yet we must forgive them for seeing us awry. The inner life is the real life. Yet it reaches out to touch others, it has to nourish itself on the world.

I try to create a safe place in my mind, away from my anxiety about my old symptoms recurring. Suddenly my garden, my cats, my lovely house, seem like treasures, threatened by the possibility of my being seriously ill again. The surgery was so recent I am still convalescent. I put off phoning my doctor. I keep hoping to get better, fear hearing the worst.

I am oddly obsessed with spiral and maze images, perhaps because I am reading *The Power of Myth* by Joseph Campbell. He says that the essence of the labyrinth is not its outward form but the movement it creates. It protects the centre by conditioning entry. The serpent who appears in myths coiled around a treasure is a version of the labyrinth. The treasure at the centre is the life of the imagination, Christopher Nolan's inner life, anyone's inner life. Before my first operation I dreamed of labyrinths, had earrings made in a double coil.

I long now to go back in time three months, to the days just after the operation, when I felt cured. If my symptoms do not abate soon, I shall have to consult my doctor. I can bear the symptoms but I fear the cause, and I feel very alone.

I remember just before being taken to the hospital by ambulance at night, I lay on my chaise longue wanting to escape from my body, to be anywhere but inside my own skin, even to be insentient, a stone or a stick. I could not imagine ever feeling well again. Now I think again of dying, and fear that this record may turn into a *Peony Diary*, the diary of a Japanese poet who wrote brief journal entries during his final illness, as he watched the peonies in his room fade with his life. In a way every diary is a 'peony diary' but only in the bearable long sense that we shall each one die in time. Perhaps these dismal thoughts are messages from my body, saying, "Pay attention to me; all is not well."

July 2

 I cannot go on as I am, feeling such discomfort, afraid to eat, sipping soda water and buttermilk. I phoned Dr. C. and made an appointment, though I refuse to believe I may be ill in the same way again. I was promised health. The surgeon said, the night before the operation, "You are very sick, and you have let yourself get very dehydrated, but I can make you well." I begin to feel he betrayed me.

I hope against despair that this illness is just a trifle, not life-threatening, but gone is my post-operative euphoric belief in being finally cured for as long as my life lasts. Well, I was fortunate to experience that fantasy for three months. It had to be an illusion.

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July 4

 I went to see Dr. C. at 10 this morning, then to the clinic for an X-ray. The woman clinician seemed sorry for me. If I arouse her pity, the news must be bad, but I have to wait for the doctor's report. I walked home in spite of my discomfort because I wanted to look at my neighbourhood, the familiar paths which I may soon be wrenched from again. I rested on my chaise longue until Dr. C. phoned: bad news, but I believe I knew it all along, because I know the symptoms so well. The intestinal twist has recurred and surgery will be required again.

Dismayed, I pack my bag, make essential phone calls, leave messages. My doctor made an appointment for me to see Dr. S., a new surgeon, at the hospital. The doctor who did the first surgery is on his honeymoon! So doctors have private lives. I think, how can he be away taking his pleasure when I need him? Then I think how strange it must be for a gastric surgeon to make love; he knows so much about the body's complex and bloody insides. Maybe this makes him love its suave envelope of skin even more.

A friend drove me to the hospital, insisted I not take a bus. I endure a barium X-ray, because I know it is for my own good. The results are clear: some kind of blockage. Dr. S. does not wish to do unnecessary surgery so soon after the first operation, so he has put me on a clear liquid diet for two days. If nothing changes, he will operate. I have a two-day stay of execution.

I asked my doctor for tranquilizers to keep my anxiety down and I spent last night in a 'drench of sleep'—Dorothy

Wordsworth's phrase. Such a relief to wake in my own room, my house. I reread what Andrei Sinyavsky writes about sleep:

How good that all people sleep, that we all have the gift of sleep and that after the follies of the day, we can plunge into it, our eyes protected by coverings of skin, and set off swimming in this ocean, together with all other creatures, and come up again washed by the miracle which nightly spirits us away, only to throw us back on the shore with the gentle reminder: go and live, live again! . . . (76)

I relish every detail of my life: the pale blue sky, the blue ocean in the distance, my fuchsia blooming red and purple in its blue urn. This is an interstice in normal time, slowed down somehow. Perhaps something may become visible which is hidden by the rush of daily life. The urgency has gone out of these days, partly because I do not want them to end. When they end, my fate will be sealed.

I must not fear the future. I did not expect to be recording another medical crisis in this diary; I thought the ordeal was over after my first surgery. I'll change my life, my diet, do anything, to make sure this does not happen again.

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July 6

 I feel light-headed, perhaps because I have been on a semi-liquid diet now for several days. My tendency to ignore my body's symptoms came close to killing me before the first operation. I cannot escape what is in store for me. Take the cup and give thanks. Joseph Campbell in *The Power of Myth* says that if we accept life completely, without reservation, we shall be transformed. He says that the scarab, the Egyptian dung beetle, is an image of transformation: initiates into mysteries were called dung beetles. The dung beetle pushes in front of her an egg, wrapped in dung, out of which new life will come. It is an image of regeneration—new life out of something base, refuse.

The thing is: we have our salvation in our possession, in front of us, the egg wrapped in dung—the accumulation of anger, fear, memory, attachment, hope, and love—the whole thing. And in it lies our salvation, not elsewhere, though we continuously look elsewhere. We already have everything we need to be transformed.

July 9

 My fate is decided. It is to be surgery. Dr. C. says I should recover more quickly this time, and there should be no recurrence. Tomorrow I must be at the hospital Emergency ward at nine in the morning. I expect to survive but I need something assured in the future to make me believe

that it will exist and I in it, so I begin to plan an overnight camping trip in late summer when I have recovered.

July 10

 At last, a bed in a hospital room. Before coming to the hospital I got up early to enjoy the fresh morning in my garden. I scattered rose petals and lavender on a glass dish to dry for sachets while I am away—a gesture to ensure my return. I spent hours on a cot in the Emergency ward before a bed in this room became available. I was patient, I know that the nurses and doctors are doing their best, that triage is fair. I am grateful now to be near a window, so that I can see the sky, the mountains, and feel a breeze. Glad, too, that I brought my diary. Writing externalizes my experience, oddly reducing rather than increasing self-absorption, because it is a gesture toward the world, and toward the future: a saving act always mercifully easy to come by, requiring little strength. My diary was the first thing I reached for when I was brought back to my room after the first operation, to scrawl in it the good news: I have survived.

Hours later now and still no operating room available. But the surgeon came in and promised he will operate today even if he has to do it at midnight. Now I think again of the *Peony Diary*. Shall I survive to write to-morrow? Does writing make my recovery more or less sure? Answer: it has nothing to do with it, but while I write, I live. Dying is no more words, no hand moving across the blue-lined page. I

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would like to take my journal to the doors of the operating room, writing every minute, trying to fend off, or to salvage something. I fear the oblivion of anesthetic, and its aftermath: nausea. I think of sitting at my word processor when I am home again: an image to hold on to, a picture of the subsequent, when all this is over.

What I am doing is pushing my little ball of dung, of worry and fear, and I have to believe that inside it is the egg that contains my salvation. You cannot choose your dung. It is what you have accumulated through your life. You knead the dung into a protective covering for the egg. It is precisely the dung, the residues and squalors of life that protects the egg. And I, at this moment, have collected a ball of dung so thick with fear and worry that I can scarcely believe that inside it is the shining egg of my salvation.

To live is to suffer. I am glad to be in a room with other women patients. It awakens compassion. All of us here are reduced to the fate of our bodies. My life, my garden, seem infinitely far away and precious.

Now it is evening but it will not be dark for a few hours. Still no operating room available. I am glad I had time to gather together a few books to bring with me. I read the Rilke poems I love:

*There is no place
That does not see you; you must change your life*

and

*Your house is the last before the infinite
Wherever you are.*

This line holds even more meaning now as I lie here waiting for surgery.

I used to fear hospitals, their anesthetic smell, their machinery, associating them with death, but after my first operation I loved the hospital, its healing devices, its benign technology. After that surgery I felt enclosed in a cradle of love and care. If it was true then, it is true now. I must summon it up. I felt full of joy to have cheated death for a while, and the hospital was my accomplice. I used to think hospitals were for people to die in. Now I believe they are for people to get well in. After all, I was cured—for a while—the first time.

But to be back in hospital, waiting for surgery again, is unnervingly *deja vu*. I feel like a recidivist, and guilty, too. I think of my past self, living from day to day, unaware of what the future held. I recall the picture of my sister and me, taken when I was about two, my sister, three. It is a studio picture—how could our mother afford it?—heads and bare shoulders, a wide ribbon or shawl wound round, binding us together: a period piece. The child I was holds her life inside her like a coiled ribbon she will unwind. I would like to creep back inside that child, still safe, and warn her of what life has in store, strengthen her.

I think of Kundalini, the coiled serpent in Indian diagrams of the body. I do not believe in her, but I imagine her inside me, with a crimp in her that has to be fixed. Then I shall be well, my energy freed.

Now I have been prepared for the operating theatre, robed in green like a ritual sacrifice to regeneration. It is called a theatre, I guess, because an operation is a kind of

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performance, with special costumes, props, cues, a beginning and an end, a sense of crisis, and the drama unfolds in time. Green, not white, is the regulation colour now, perhaps because it is the colour of hope, new life, or because blood smears do not look quite so shocking on green. Now I am reduced to the fate of my body. Morning seems far away. Shall I live and write in these pages tomorrow?

Soon it will be evening. The cramps are worse and more frequent. I hope they come for me soon.

July 11

 Morning now. They took me to the operating room nine hours after I was admitted. I was relieved to be wheeled down the hall, even though I felt I was being wheeled to possible death. The operating room was familiar from the first surgery. I like its courtesies, the sense it gives that one is in competent hands. A very kind nurse held my hand after I was strapped on to the operating couch and told me to think of something pleasant. When I am dreading some ordeal I always repeat in my mind a poem I have memorized. I had already started Francis Thompson's "In No Strange Land":

*O world invisible, we view thee,
O world intangible, we clutch thee,
O world unknowable, we know thee*

As I reached the third line my eyelids became irresistibly heavy, I felt tears welling out from under my closed eyes, and then blackness.

July 12

 Yesterday was spent drifting in and out of post-anesthetic sleep. Now I see I am linked to tubes leading to drainage systems: a tube down my nose to my stomach, a tube draining the incision in my abdomen, an intravenous needle in my arm, a catheter draining my bladder. The tube down my nose and through my throat is hardest to bear because I keep trying to swallow, and my throat aches.

Where does the mind go under anaesthetic? The drug is so pervasive the mind must recede to a tiny point of light, like the pilot light in a gas fireplace. There is no memory of surgery, in spite of the violence that is done to the body during this amnesia. There is something frightening about this gap in consciousness, merciful though it is.

I open my eyes and the room springs into view, as if its being there begins with the *fiat* of my eyelids lifting. I close them and it vanishes. My sister, a nurse, told me that the sutures are not really necessary, that healing begins as soon as the incision is closed. I imagine the cells of the incision leaping to one another in love, which joins and heals. I have cheated death for now; I have a reprieve from his arms for a couple of decades. My surgeon, master of entrails, has prognosticated that I shall live. In my mind is

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a line from a poem by Conrad Aiken, “*Shining I rise from the starless waters of sleep.*” Anesthetic sleep is starless. The poem is called *Senlin*. I love its linking of the everyday and the ultimate:

*It is morning: I awake from a bed of silence,
Shining I rise from the starless waters of sleep.
The walls are about me still as in the evening,
I am the same, the same name still I keep.*

Joseph Campbell says that on the Aztec path to salvation the soul has to pass through the realm of language, where the words of the gods are written on scrolls. In ancient Mayan lore, an appointed person, often a woman, would pierce her tongue ritually with a sharp instrument, the blood dripping into a bowl containing blank scrolls. Later the blood-stained scrolls were burned so that the smoke could ascend to the gods. There were no words: the blood is the message, the evidence that the necessary sustaining act has been performed. The gods have been fed. In the operating theater there are no words: the incision, the blood and the body are the message. Once that is over, one comes back to the realm of words, which is where I live and have always lived. I do not have the strength to brush my hair but I can write on these pages. The writing is my thanks to the gods for this day, for more life.

People who bring their bodies here to be healed are wrenched from the cultural context that bestows meaning and authority on them. Through the open door of my room I see a man in slippers and dressing-gown walk by, trailing his intravenous gear, leaning on a nurse's arm. In

his mouth a cigarette holder, an unlit cigarette! He could be an executive, a carpenter, a politician, a professor. Here, these sources of authority have deserted him, along with their props—the suit, the briefcase, the tools. He is a body, needy, healing—if he is lucky.

When we are ill, we fall back into nature. The threads of thought and action that link us with culture weaken and we are briefly disoriented during convalescence, as we pick up these threads again. Because I have my journal I can retain, here, some sense of my culture, my life: As long as I have a scrap of paper and a pencil or pen, I can assert myself over circumstances by writing them down. This links me with all those, more heroic than I, who have scratched words on cell walls, written with burnt-out matches on stone, in miniature script on tiny bits of paper in prisons.

July 13

 I am in a room with two other women, one waiting for surgery, one recovering. The tiny, elderly woman kitty-corner from me has had drastic lung surgery, the woman next to me is to go in for gastric surgery tomorrow. They both comment on how bright I am, how I sit, propped up, and write, smile, do not complain. How could I complain? I am alive, am I not? The French poet Lautreamont says that the greatest blessing is to be born. I agree, and add: to be still alive.

I'm going to ask my daughter to bring my pencil

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crayons so that I can draw the flowers in vases on our tables. I remember when I was in hospital with an abscessed ear as a child I made a book of poems on one page and drawings on the other. I recall the joy of making that book. How I wish I still had it. Such things contain like a quintessence the absorbed happiness that went into their making, a distillation of productive joy.

Later. I wake crying, after a brief daytime sleep. The truth is, after my post-operative euphoria I am low in spirits and wonder if I shall ever be well again. To take me out of myself, I have started to make notes about Lucie, the little woman in the corner bed. I want to put her in a story, so I write down what she says. She is charming, vulnerable and strong at the same time. She calls us—me and the woman next to me—‘girls’. She says, “Girls, I’m sorry I lost my dignity today, when I gave that little baby whine. I was so ashamed.” She says, “Men, they have their big egos, but we women have our feelings. Maybe we feel too much.” She weeps if her husband is late, then scolds him for staying too long. She cannot eat hospital food; her husband brings her borscht in a plastic container. She says, “Tell me how much you miss me”. Then (to us) “I have no shame. I just ask him straight out.” She says, “Everything gets sad, because that is what life is all about.” She says to the nurse, “I’m so weak I can’t even yell at my husband any more.” Her grandchildren call her “baba” and “darling.” I think it is she who taught them this language of love. She is like a frail bird, about to take flight; volatile, like weather: sunshine and rain mixed. Her name means ‘light’. I’ll use that in the story. She is tiny but she shines, sometimes blazes.

Making notes for the story about Lucie, I begin to feel

the possibility of unbothered life. Excited by this story, I think perhaps a new creative period will begin for me.

The lump in my throat from the tube is hard to bear.

M. biked over, brought me some wild roses she picked on the way. They remind me of my childhood —the banks of sweet-smelling roses growing wild by the Similkameen River.

I am not allowed to swallow any liquid for another two days, until the tube is removed from my nose, but I have been given ice water to hold in my mouth and spit out. It is unbelievably delicious. I feel blessed just to be able to taste it, to know that cold water has a taste.

My struggle is not to blame myself for this episode, to begin hoping for the future, for my small life to continue. I can scarcely imagine being well, really well and carefree again. I look drained and drawn in the hospital mirrors, half dread going home. My schemes of life, my stories, my walks to see the ocean, to visit my children and friends, seem lost to me.

July 14

 I do not talk much because the tube is affecting my voice; I am quite hoarse. I try to imagine a space around it in my throat, but that does not help. Dr. S. came in today and tied it off, and if I remain without nausea for a day, it can be removed. What a relief that will be. It will make walking easier, too. All these tubes, liquids: the inside made

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outside—a tube with attached bag draining my abdomen, another draining my bladder. And the intravenous, replacing the liquids lost! Even though it is delicious to hold ice water in my mouth, I do not feel thirsty, just dry in my mouth. Thirst, I realize, is not in one's mouth, but in the deep recesses of the body's rivers, which the intravenous replenishes.

Today I noticed another small bag dripping liquid into the long intravenous bag and asked the nurse what it contains: gentamicin, a liquid antibiotic against possible gastric infection, which I show no signs of but which is a life-threatening risk after abdominal surgery.

The doctors are lords of this world. They saunter in and out of rooms, pull drapes closed to closet themselves with patients, open them again, give orders to nurses. Difficult to imagine one of them sick, in pain, dying, lying in a hospital bed. Yet they have bodies too. I remember reading somewhere that the main difference between people is the difference between the one lying down and the one standing up. How I envy the doctors' savoir faire, their uniforms of knowledge and authority. Patients say "my doctor" as if they were the only ones on whom the doctor bestows his, her, attention and expertise. This is partly because the hospital room feels like the confines of the world. It is hard to believe in a world outside it.

July 15

 Yesterday the tube was removed from my throat. I closed my eyes while the nurses pulled it out like a long, bitter-tasting worm. I did not gag. Now I experience the bliss of swallowing sips of ice water. I begin to believe, "All shall be well; all manner of thing shall be well." If I am not nauseated, I shall be able to drink juice tomorrow.

My spirits go up and down. Despite reassurances, I fear being ill again. One never knows what is in store. The person I was, who felt so safe, was in fact heading for a medical crisis again. I summon up images of the ocean, my walks by the sea, my dear cats who, my daughter tells me, lie in the hallway by the door, waiting for me to come home. I want to join the living again, to rebuild my life illusions. When I read Ibsen as a child, I was devastated by his notion that we are sustained in life by illusions. I wanted not to be deceived, to live in relation to truth. I thought, as long as I live in an illusion, I am not safe from disillusionment. Yet now I believe with Wallace Stevens that we are sustained precisely by fictions, without which life is inconceivable. These fictions, the stories we tell ourselves, are the imagination's mercies.

Dr. C. comes by, notices my diary on my tray. He says, "Is your surgery in there?" I say, "Not the surgery, but the before and after."

I have been through this twice. I must begin and end each day with a prayer of thanks, just for being alive. I remember when I came home after being in hospital with pneumonia as a young mother; I resolved never to forget the happiness of walking into my house and seeing my small children again. The intensity of the moment when

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I walked through the door, touched my children again, faded, as such moments do fade, but it still lies there, a treasure entangled in the narrative threads of my life, and I can relive it in imagination whenever I choose.

In fairy-tales describing the christening of princesses there is always a malign or dark fairy with a sinister gift. What this means is that no matter how beautiful, wealthy, seemingly lucky someone is, misfortune will strike. No one can be safe or lucky all the time.

Simone Weil says the essential human condition is affliction, masked by luck, health, pleasure. Similarly Christopher Nolan talks about the *TABs*, the Temporarily Able-Bodied ones. But what happened to me is not an affliction, just a brief misfortune, because it is transient.

July 16

 Amazing how exotic flavours are, after just a few days of not tasting. I was given consommé, but it was too salty, orange juice too sharp, tea too bitter, lime jelly too synthetic. I managed to drink some apple juice and M. will bring me guava pear juice tomorrow.

My stitches are to be taken out today and in two days I can go home. I shall miss Lucie. She says every tiny thing, each blossom, each shift in season, each stick, stone, gives her happiness. Afterwards she laughs, “Do you notice how wisdom is starting to pour forth from our mouths? I’m going to have to lie down.” She seems so frail, yet has such

strength. I'll never forget her.

I can scarcely imagine being really well and carefree. I know I will recover more quickly this time. I long to go down to the ocean again, return to my normal life. I struggle with this in writing, my only way. Misfortune is embedded in our lives like ore containing gems, precious metal. We have to refine the ore to get at the gems. Writing helps me do that. And it is a way of disburdening myself of my life so that I can turn my mind to what will come next. It almost literally lightens life, because what has happened has been deposited between the pages of a book, and can be forgotten.

I recall the lines from *Lear*: “*Nothing, almost, sees miracles, but misery.*” I just experienced, this minute, a fresh breeze on my face from the open window, and a few days ago I experienced the miracle of swallowing and really tasting cold water. I begin to believe I shall be well. I imagine going out to do errands, walking on the beach, being part of daily life again. That will be miracle enough.

I recall an old poem,

*‘Tell me, poet, how do you bear
The wild, the sad, the terrible ways?’
‘I praise.’*

I don't remember the rest but I must live by the response. I shall be like the revenants in the poem by Wallace Stevens, weeping with joy to see even the most impoverished traces of life, weeping with relief to see my house, my cats.

Just seven days ago I arrived here and began this ordeal. I shall seek out narratives of people who have lived long

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and well after surgeries. Excited and uneasy about going home, picking up the threads of life. I am told to do no lifting, heaving, vacuuming or lawn-mowing for six weeks, but I am allowed to go for walks, so I can begin to reclaim my small world. This notebook isn't finished so it will turn from a hospital record to a convalescent's story.

July 18

 Now I am home and sit again on my porch in my absurd blue felt hat, bought long ago at a market in Florence, to shield me from the sun. My dear orange cat is at my feet. To be absurd is to be alive. I have not yet listened to my phone messages; I cannot summon the energy to respond to them, or to sort and open the pile of mail on my dining table. I drink orange juice out of a wine goblet and try to reconstruct what Samuel Johnson calls my interrupted schemes of life. This is almost too much happiness. I read the Wallace Stevens poem I thought about in hospital, "Large Red Man Reading":

*There were those that returned
to hear him read from the poem of life
Of the pans above the stove, the pots on the table,
the tulips among them.
There were those that would have wept
to step barefoot into reality
That would have wept and been happy,*

*have shivered in the frost
And cried out to the cold to feel it again,
have run their fingers over leaves
And against the most coiled thorn, have seized
on what was ugly
And laughed. . . .*

These lines express perfectly what I feel about life as I return home. I have stepped into reality again: roses blooming abundantly in the garden; the ocean, the sky. Even if I were snatched out of this daily joy again, I have had a whole day; it is almost enough. I water the geraniums on my balcony, feed my cats, put away the groceries I bought for me. I think of Lucie, still in hospital. I hope she can come home soon.

July 19

 Next day, and I am exhausted from the effort of showering and washing my hair. So much for my dreams of tidying my house, sitting at my word processor. Still, I have another perfect summer day of leisure. Perhaps I was wrong to stay up all day yesterday. I was quite worn out by the end. My eyes in the mirror look deep-set, like my mother's. I quickly put my sun-glasses on. I must remember the picture of myself as a little girl gazing out from the oval frame, and try to be true to her. I have to love the distance between me and that child, because that distance is my life

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and I cannot change it.

Strange, how we prepare for our futures without knowing what we are doing: just before I became ill again, I went to the hardware store and bought small plastic shell shapes to stick to the bottom of the bath to prevent slipping. I could not have showered this morning without them there. My long hair is heavy and I feel strangely unsteady, a sensation I do not recall having after my first operation.

So I sit on my porch under my parasol and read Wallace Stevens:

*Life is a bitter aspic; we are not
At the centre of a diamond.*

but I feel as if I, alive and well, am at the centre of a diamond. And

*Natives of poverty, children of malheur
The gaiety of language is our seigneur*

This I do believe. The gaiety of language has always been my comfort.

July 20

 Now, a day later, I still have little energy and am established again in my chair with books and journal to spend another day on my porch. My blue felt hat is too hot so I suspended my rainbow striped umbrella from one of the cross-beams that holds up the glass roof of my balcony. Umbrella: little shadow, though the word for a sun shade is “parasol,” meaning sun-shield.

This is summer perfection: a red freighter moving into the narrows, the swish, swish, of the sprinkler. I have not gone down the spiral stairs into the garden. I sit at this elevation and gaze down. I wear dark glasses and read Virginia Woolf and Lady Murasaki’s *The Tale of Genji*. A few phone calls, an hour at my word processor attending to a few letters. The evenings are long and I can sit on my porch until dark. If I tire of reading, I write in my journal or look out at the ocean. I weary of my own company and miss the women in my hospital room, the sense of shared plight and mutual sympathy, the talk. I especially miss Lucie, her sweet courage. I fear becoming self-absorbed, but have not the strength to stir. I remember lines from Housman, whom I loved to read as a teen-ager:

*Torquatus, if the gods in heaven shall add
Tomorrow to today, what tongue can tell?*

Well, they have added today and I accept it as a gift. But my writing is my chief escape from myself and I have no energy to write except in this notebook. Even phone calls tire me out, so I read until I can scarcely see. I am weary of spiritual quests. I want images—poems, *Genji*, Virginia Woolf. One

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thing I love about *Gengi* is that the lyrical, the aria of feeling, is formally expressed in small poems which star every page of prose like flowers in a landscape. English fiction has never really solved the problem of the aria in prose fiction but the Japanese did it from the beginning, probably because lyric poetry came first and Japanese prose narrative developed as a link between poems to provide context.

This account, these words, go nowhere, but it steadies me to write and objectifies my life a little. Genres of the diary: the song of praise, the complaint, the introspective analysis, the descriptive vignette. I love *Gengi* and Japanese diaries like *The Gossamer Years*, which I am now reading, because they consist essentially of these small genres, with a slender narrative line. *The Gossamer Years* is an orchestration of feeling in the context of a single life story: the failed marriage. Is this its attraction for me? The enchanting *The Pillow Book* has no narrative line—just small, embedded anecdotes, lists, poems, character sketches, complaints. Sei Shonagon, who wrote *The Pillow Book*, was, like any diarist, a jotter, who kept her notebook close so that she could instantly record transient impressions.

When I have the strength to sit at my desk and write, I'll start the story about Lucie from the notes I made in hospital. It is a kind of link between then and now. I feel the struggle to get back into culture, life as it is lived.

I listen to classical music on the radio, to what is called "News." News has little to do with information. It is a coded demonstration of the rituals of real or fabricated concerns which gives people their vague but shared sense of reality, of the social fabric.

A. asked me to come down into the garden to join her

and L. but I declined because I do not want them to see how weak I am. I feel strong enough when I am sitting in my chair but when I get up I have to hold on to something in order to stand steadily. The prospect of walking down the spiral stairs, let alone walking on the grass, is unnerving.

This odd unsteadiness, which I can scarcely admit and have not mentioned to anyone, is worrying. I seem to remember walking fairly well when I was in hospital. Now I cannot even cross a room without supporting myself by touching walls and furniture. If I move, even turn my head, things close up and in the distance swirl and tilt. I am fine in one place, but the transitions are dizzying. The chair or the chaise longue seems to rise up to meet me. Why? Since I find walking so difficult, I tend to sit or lie down most of the time. Today I gave up and lay on my chaise longue for hours. If I lie down or sit perfectly still or stand without moving, I feel normal, but the slightest movement, even the shift from sitting to lying down, makes the whole world swirl around me. It is as though I have to function in a world that has become drastically unstable. Yet I do not feel nauseated. Tomorrow I shall practise deliberately walking about my house; no one can see me there.

And what would I be doing if I were well? Gardening, walking. It is odd, this convalescence coming so close to the previous one. Perhaps I am just weaker because my body had to undergo these two traumatic intrusions three months apart. Time seems real; I say "I". The pale moon appears in the sky as it appeared to Lady Murasaki a thousand years ago. I must be grateful to be alive after all, but to be so apart from life is oddly numbing. I long for something to read, to carry me away. I tried Doris Lessing's *The Four*

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Gated City, which I have long planned to read, and I love Lessing's attention to detail and her rough insistence on stripping things down, but she is full of dislike. She is often irritated by the people she invents. In this book she moves toward the visionary. Well, why not? I would not mind being there.

July 21

 This morning I managed to walk down the stairs, clinging to the railing, and stagger across the garden, determined to walk down the lane behind the garden, with my two dear familiars, my cats Pandora and Marimekko, following me. I had to cling to garages, fences and shrubs to make my way along and back. I have to look at my feet to see if they are making the motions of walking. If I look about, all I see is a surrealistic image of tilting, swaying trees and houses. I am very discouraged. I finally phoned my sister in New York, who, being a nurse, might know something, and told her about my new symptoms. She says my blood pressure may be low. I'll have it measured when I go for my post-op check up with Dr. S.

I did manage to type for two hours yesterday—a first draft of my story about Lucie. When I sit at my word processor, I feel normal, unless I move my head, but as soon as I get up, I stagger and the room shifts and swerves, yet it is not exactly dizziness. It seems to be outside me—a property of the world. When I move, or even move my head,

the things around me tilt and jiggle. They look the way an earth tremor feels, but a tremor is usually quick, whereas this does not go away. It is radically unnerving, disorienting, I reach out to grab something that feels stable. It is *terra infirma*. I stand still and the world returns to normal.

July 22

 Today A. and L. took me shopping in their car and it was a joy to be in my village again. I leaned on A. while I walked, which is amusing, since she is very pregnant and ought to be leaning on me. Large open spaces, like parking lots, are threatening. I look to the far side and they seem like chasms, quite impossible to traverse. Streets look too wide for me to dream of crossing. Once we were in the market, I leaned on the grocery cart and achieved a semblance of independence, though I had to stop and stand still in order to see things on shelves, read labels and prices. While I am walking, they are a blur. On the way there, we stopped at D's. I did not want him to see that I could not cross the road on my own, so I stayed in the car.

I watch my neighbour in her yard, doing garden chores, and I lie on my chaise longue, useless. I read my new book about the private lives of the ancient Romans, to get a perspective on my small life., Every period is 'now,' 'on the edge,' 'modern' 'The people at court in Lady Murasaki's time were obsessed with being up-to-date, 'nowish.'. For us, it seems, the future will surprise us with its novelty, it

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has not happened yet. But for everyone who ever lived, it seemed so.

I hate being so physically weak. I call it “weakness” but it is unlike anything I have ever felt before. It is rather like being absolutely, infinitely drunk. I stagger and the world seems to shift and totter. What is the matter with me? Shall I recover? Did my brain suffer some mysterious damage during surgery? I welcome phone calls. Other people’s lives of camping, traipsing about, seem wildly adventuresome. The camping trip I planned before surgery seems now an unobtainable fantasy. I want to leave my house, to go out, to be part of the world, to get on a bus, go into a shop, but it is simply out of the question. My world has shrunk to the four walls of my house and – with difficulty – the lane behind it. Today I go to see the surgeon for my post-op check-up. Perhaps he will tell me what is wrong. T. is coming tomorrow evening to drive me to a park by the ocean so that I can at least sit on a log and look at the sea.

July 23

 A relief to report that when Dr. S. observed me lurching down the hall to his office, clinging to the walls, he asked me with alarm if I have always been like this and I replied, “No, just since I came home from hospital.” He checked my blood pressure, found it fine, and sent me to the hospital to be tested for anemia. If my blood is OK, I must go to my family doctor who will tell me what to do

next. It was reassuring to have someone in authority confirm that my condition is not normal. Before I left, I asked him if I can keep in touch with him. I felt I didn't want to be abandoned. He said, "Yes, but only if it has to do with the surgery." I wonder what he meant by that?

C. drove me to the hospital for tests. The huge lobbies loomed and shifted as I clung to walls. A man asked me if I needed a wheel-chair and I declined. I resolve to manage this on foot. I scarcely care any longer what people think. Afterwards C. drove me to a supermarket, which looked so beautiful, so abundant, I almost cried. The people walking about, gathering provisions, living in a normal, stable world, seemed blessed beyond belief. I steadied myself with a grocery cart and bought some treats: guava juice, ice cream, papayas. If I am to be confined to my house, I want a few delicacies to comfort me.

July 24

 Morning. Gladiola in bloom. It is that time of summer. I think of Andrew Marvell's poem about measuring time by flowers, about a sun-dial made of herbs and flowers. He says that the sun runs through a "fragrant zodiac." Since time, whatever it is, cannot be stopped, and we seem obsessed with measuring it, it seems pleasant and pastoral to do it with flowers.

Later. L. drove me to see my family doctor. She seemed concerned and said I must see a neurologist at once. She

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said something about the drugs I was given in hospital but did not elaborate. At least someone is paying attention, giving me some clue to what is happening to me.

Now I begin to be afraid. What if some irreparable damage has been done to my central nervous system? What if I shall never be well? I watch people walk and it seems a miracle. L. took me in his car to the bank to do some business, supporting me without making my difficulties obvious. I felt capable and normal to be attending to money orders and bank deposits. But I could not have walked into the bank without help. What if my condition does not change? Well at least I can see. I thought of old Gloucester, in *Lear*, eyeless, stumbling his way toward Dover:

Men must endure

Their going hence, even as their coming hither.

Ripeness is all.

Now I have a sense of community with all who have left behind them the condition of the 'temporarily able bodied'. I watch with interest and sympathy anyone walking with a cane or a crutch. Looking at a ballerina on TV last night, I thought that a beautiful, able, skilled human body is one of the loveliest things in the world.

T. took me to the beach in the evening. It is where I wanted to be but could not get to on my own. It was a mixed joy. The tide was up, so we did not have far to walk. I had to lean heavily on her to get to the driftwood, especially when my feet sank into the sand. I love to be at the edge, where the reach of the tide is marked by a rippled line of sea weed and tiny shells and sticks. I love the way the light

seems to be sucked out of the sand as it dries when the waves swirl back. It is a place of reliable sameness, perpetual change. I recall the joy I felt when I first read about 'Chaos', about fractal shapes, and realized that the tidal edge I love to look at is fractal—infinately varied yet always self-similar. I could not walk on the sand or the stones, so we sat on a large drift-wood log and I cried with mingled happiness, to be there, and worry, about my fate. Shall I ever be able to walk by the ocean again, unaided?

July 24

 On my porch with my cats. A warm summer evening. Well, it is settled. I have seen the neurologist. I know what is wrong with me. The gentamicin I was given for five days after surgery as a preventive antibiotic has permanently destroyed my vestibular-oracular reflex, (VOR) the centre of balance in my inner ears.

The basic test is absurdly simple. The neurologist placed in front of me a printed text and asked me to move my head from side to side. If the letters turn into an illegible blur, that means that your balance system is impaired. They did. It is. He seemed almost pleased. He smiled: the diagnostician's delight in closure. It is pat, it fits, there is no doubt. Destruction of the balance system can be caused in various ways, but given my medical history, the fact that I was given gentamicin after surgery, in my case the destruction was gentamicin-induced.

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Dismayed, I ask, “You mean it will never get better? I’ll always be like this?” “It’s permanent,” he says, “You’ll just have to get used to it”. How can he be so matter of fact, so calm? I want to protest. It can’t be true! “If gentamicin does this to people,” I ask, “why is it prescribed?” “For very good medical reasons,” he replies. “Gentamicin is specific for the kind of gastric infection that may occur after an operation like the one you had, and a toxic reaction is rare; it usually happens only after several weeks on the drug.”

At least my bewildering condition begins to make sense. A connection has been established. My vestibulo-oracular reflex has been permanently destroyed. Millions of tiny follicles have lain down and died. This is a fact and I cannot change it. All I can do is adjust. Normal walking, he tells me, depends on the balance system, and on three other functions: sight, cerebellum, and tactile sense. I have to learn to compensate for the loss of the first by developing the other three. It will take time, and my walk will never be normal. I shall never be able to walk alone after dark, to walk downstairs without looking at my feet, to walk on ice or snow, to walk alone into the sea to swim.

I stand swaying in his office, listening to my life sentence, feeling all these customary and loved activities leaving me. I have to live forever inside this strange, shifting world. I want to walk out his office door as if by leaving the diagnostic scene I could leave behind the truth about my fate, but as I stagger out into the hallway and lean against the wall I realize that I carry this new, unnerving world with me wherever I go; I cannot escape it by walking out any door. I am to go to the hospital for more tests to confirm his diagnosis.

My habitual response to bad news kicks in. I tell myself it could be worse. At least I do not have MS or a brain tumor. And now that I know what is wrong I can begin to get up on my feet and try. I am already past the first, disorienting sensation of being drastically unable to handle my body in space.

After the neurologist, L. took me to a mall and I asked him to leave me in a drug store, where I took a tube of toothpaste off a shelf, walked to the cashier, holding on to shelves as inconspicuously as I could, paid for my purchase, and managed, with great concentration and some clinging to walls, to walk alone a little distance to the kitchen shop where I had arranged to meet him. A triumph! At least it is a beginning. In the parking lot, I staggered before getting into the car, and a man laughed. I feel like saying to him, "Don't laugh. You, too, are only temporarily able-bodied."

July 25

 I feel less anxious, relieved to know the reasons for my condition, that it will not get worse, and determined to learn to function. Today I walked down the lane without holding on to anything. I staggered from side to side, but there is no one to see me, no one to bump into. My concentration on getting my feet rightly placed is disturbed by the shifting, teetering and swaying of the world around me.

Lying in bed this morning, putting off getting up and having to cope with the steps and gestures that start the day,

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I began to map out routes between here and there, imagine myself taking a bus, walking from the bus-stop to the college to teach. When I lie still in my bed, I feel normal. Then as I struggle to my feet and stagger down the hall to the bathroom, the world swaying around me, I realize I face another day of learning to function in this bizarre world that will not keep still. The maps in my mind dissolve into impossible dreams. The temptation is to stop moving, to sit or lie down. I fight despondence by trying to make realistic, immediate plans. I have managed to walk down the lane by myself; soon I should be able to walk a little distance on the road in front of my house, but that will be harder: there are not so many things to hold onto.

Later: I just walked to the park two blocks away with A. and L. The truth is, I am terribly impaired, really handicapped. I cannot look left and right at curbs without stopping completely, cannot step off a curb without watching my feet. I have to look either straight ahead or at my feet, in order to attain even an approximation of normal walking. I have achieved a fair degree of competence in my house, bare-foot and with known walls defining spaces for me, things I can touch to steady myself. But on the street, in the open, the peripheral world teetering and swaying, the trees and buildings looming and shifting, I am seriously disoriented. The thought of walking to the bus stop two blocks down hill, fades.

July 26

 I am drastically cast upon my own resources. Even inside my rooms, which I know so well, I have to watch my feet. It is as if they have lost their ability to function without my looking at them. My grip on the floor is improving. But I long to go out into the world. I envy people who are going camping, swimming. I cannot even walk to the park alone. I start to read a book, put it aside. I read once that a cure for depression is to learn something new, so I read Stephen Jay Gould's essays about fossils, strange creatures, plate tectonics. I put Doris Lessing away. She is strident and modern. I prefer Charlotte Bronte's *Shirley*. Bronte is passionate but also compassionate and thoughtful. I like her mind better than I like Lessing's and what a novel really gives is a tour of a mind.

I feel a kind of grief when I hear about friends moving to a lovely new house, people visiting them. I cannot even walk two blocks to the park alone. I feel half imprisoned by invisible constraints, but the constraints are in me, in my malfunctioning body. I think of the line from a poem by Thomas Hardy: "*They move to a new, high house*" – then the refrain, "*Ah, No! The years! The years!*" It is as though I have a kind of obbligato or commentary going on in my mind, so that I am accompanied through life by lines from poems I have read or memorized.

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July 27

 I walked to the park again with A and L. and did very much better. I stay close to them but manage to stay upright without touching them, though I sway. This is my daily activity. Other than that, I spend a few hours at my word processor, sit on my porch or lie on my chaise longue and read or write in my journal, long for a telephone call from someone, anyone. Summer days are long. My resources are thin. “There is a world elsewhere” and I cannot get to it so I look out at the ocean, read about the private lives of the Romans.

July 29

 Today I was driven to the hospital for tests to confirm the diagnosis. In the car on the way to the clinic it was exiting to see people on the streets, walking, as though it were nothing, which to them, it is. I want to go up to them, tell them how remarkable it is that they walk upright, placing one foot in front of the other without thinking about it.

The tests are simple: I am first asked to close my eyes and try to walk straight. I fail this one. Then I sit in a chair and am instructed to try to read words or interpret images while the clinician moves my head back and forth. Impossible: a shifting blur. A test has been developed called the Dynamic Illegible E-test—DIE for short—not a cheerful acronym. A chart with rows of E’s on it (seven rows of ten letters each), in degrees of bold-face, size, and positioning,

is placed some 12 feet from the patient. The smallest row a patient can read with the head held still is regarded as the patient's visual acuity. The test is simple: the patient's head is grasped and repeatedly turned from right to left and back through to right in an arc of about 60 degrees once per second. This corresponds to head velocity of approximately 120 degrees per second. The patient is asked to read the chart again while undergoing this head movement. The change in acuity is noted.

The simplicity of the test, its reliability, and the cheapness and availability of its apparatus make it very useful. I do the test and as expected the diagnosis is confirmed. It seems that though the causes of destruction of the balance system vary, the symptoms are produced by no other condition. If you experience drastic instability of visual images when body or head are in motion—the charming medical term is 'bobbing oscillopsia'—your balance system has been damaged or destroyed.

The next test, the ENG (Electronystagmography) consists of lying prone on a cot while first warm, then cold, then ice cold water is injected into your ear canals by syringe. This procedure fools the brain into thinking it is spinning around. Then the velocity of the induced horizontal eye movement is measured. If the results of the test with warm water are within the normal range, the test does not proceed to the cold water stage. In my case, the coldest caloric test was done. There was no measurable eye-movement. There is a subjective component to the test, too: a subject with an intact balance reflex will experience various degrees of dizziness, even extreme nausea. All I felt was the change in temperature as the water became colder. This test

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confirms the diagnosis and the results of the DIE test: there is no trace of the balance function.

I was told that the underlying cause of balance disorders is the death of sensory nerve cells through a complex chemistry of protein production, which causes them to self-destruct.

So the message from the neurologist was confirmed. My condition will not improve, but with practice and concentration my walk will become more normal, though I will never be able to walk in the dark alone, will have to watch my feet as they walk down slopes or stairs. The neurologist told me to get a cane, the clinician tells me not too, because I would become dependent on it.

I relished the attention I received at the clinic. I have been feeling very isolated, cut off, abandoned by the medical system that got me into this plight.

As we leave the clinic, I see a nurse pushing a wheelchair with a woman in it, beside a man walking with a white cane, and I feel lucky to be on my own feet, but the miraculous facility of ordinary people, stepping off curbs, crossing streets, seems beyond reach. I am living in my body in a new way. I have to pause and look carefully at the slightest elevation or downward step. I have to think about how to coordinate my feet with what I see in front of me and in order to do that I have to stand still.

July 30

 I realize that I have to be careful not to let things upset me, because if I become emotionally disturbed, my body becomes literally upset. This morning a phone call about my unemployment insurance for the summer months unnerved me and my walk was immediately affected. I had to lie down for a few hours. My still convalescent state no doubt contributes to this effect, but I shall have to try to see such upsets coming and fend them off. Emotions are a distraction that keep me from concentrating on walking.

Every morning now I walk the block down the back lane alone. I have not yet attempted to walk on the road in front of my house. It seems simply out of bounds, beyond the tiny territory in which I can function. Most afternoons I walk to the park with A. and L. Yesterday I decided to try this walk alone but before I stepped out of the lane a large truck came behind me and I had to cling to a post while it passed. Then I staggered back to my house, discouraged.

My feet, while walking, have begun to function without being continually watched, but now that I no longer have to look at them every minute while walking, I am more aware of and disturbed by my visual disorientation, the jiggling and swooping of things. I practise keeping my head still when I sit or stand, and 'spotting' like a dancer when I walk. I can scarcely imagine my village, just at the bottom of the hill, a few blocks away. It seems inaccessible, out of reach. I cannot picture myself walking that far. Since I cannot get to it, it has, in effect, disappeared.

My pleasure is to sit, keep my head still and make the world be still. The instability of images when I move is very

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tiring. It is dispiriting to realize that though my walk improves and will improve, the way the world looks when I move will not change, though perhaps in time I shall notice it less. At the moment it has a strange fascination. I shut my eyes while I brush my teeth because that action makes everything jiggle frantically in the mirror. Still, this is a new stage. Now that my feet are under better control, I am more aware of the wobbling and shifting of things that are supposed to stay in one place.

August 2

 I can now do certain chores. I dragged a bag of garbage down to the end of the garden. I moved the hose. I do these tasks slowly, concentrating hard, but they are small triumphs. I cannot carry any object that obscures my view of my feet. Sometimes I feel intensely frustrated by this helplessness, by the things I do not and cannot do. I can't change a light bulb, or garden, or even vacuum my house, because I cannot manage my body, let alone handle tools. I keep thinking I am making steady progress, then I seem to lapse, feel thicker, half brain damaged, stumble and sway. The fatigue I feel at the end of my simple, undemanding days is partly the weariness of having to pay unremitting attention to what my body is doing in space, where my feet are going.

I spend a few hours every morning writing poems or putting my stories on disk. When I sit still at my word

processor I feel normal and happy with the familiar happiness I have felt as long as I can remember: the fascination of writing. I think of Christopher Nolan, able to strike the keys of his computer only with a stick strapped to his head, and only if a helper holds his head still. How blessed am I with ten steady fingers.

I begin to think I shall not be up to working at the college this fall. Well, at least I was helped at first by not realizing how long it would take to relearn to walk independently.

I am rereading Samuel Johnson's *Lives of the English Poets*. The rigorous beauty of his prose and his bracing sense of life's ironies is very tonic. Johnson suffered from many tics and compulsions, would have been thought grotesque, were it not for the power of his intellect and his integrity. As Christopher Nolan says, we are not what others see. I love reading eighteenth century prose, written before the horrors of the twentieth century. I wonder if anyone back then suffered from my impairment, or is it too a twentieth century novelty, induced by a synthetic drug?

When I walk down the lane I can hold on to fences, bushes, tree trunks. When I walk with another person, I walk close to him or her but rarely touch, so why can't I manage to walk outside alone? The answer seems to be that the vertical, erect, stable presence of the other helps me stay upright and steady. I walk in relation to the person walking beside me. If I try to walk alone, there is no visible anchor, no one to imitate, or to touch if I stagger, and I am distracted by the swaying world.

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August 4

 I went to a birthday party for children with A. and L. and being there made me feel I can mingle with normal people in a house, but maneuvering through an unfamiliar interior was tiring and the closeness of people in a crowded room makes me uneasy because I need a little space around me in order to pay attention to how I move. I know that everyone lives in a different world, sees the world from a particular perspective, but I feel locked in with this secret perception of the world as skewed, as perpetually in motion, because I know that this image does not correspond to what others see. I was intensely relieved to get home. The truth is I am not equal just now to any social occasion.

But one must accept the world, life, on the terms offered, unless one decides to call it quits, and I have never felt like that. I tell myself that to see the world as a swirling place, when I move, is a gift, a variety. I have two worlds: a still one and a moving one. We know that the still world, after all, is an illusion. Nothing is really still. Molecules are in continuous motion. Yes, but not the kind of motion I see when I move, which looks like a property of the world, but which is a projection of my wrecked perception. I feel damaged all the time, except when I sit here at my word processor or when I draw or do some other task sitting at my table.

So what am I complaining about? About the fact that as soon as I move, even slightly, I feel drastically incapacitated. Life is not sedentary. To live is to move. Sometimes I want to turn this diary into a lament for what has happened to me. If I lamented enough, I might be able to staunch regret and give up the longing to be the way I used to be.

August 6

 My answering machine broke and I felt overcome by grief and anxiety. Perhaps my tolerance for broken things is diminished because I feel broken, damaged, irreparable. And how am I to get to a shop to buy another? I must have it because it is my life-line, one of my ways of receiving messages from the larger world which I cannot get to.

I remember reading about a sequence in one's acceptance of any dire fate: cancer, impending death. First denial, then anger, bargaining, acceptance. I do not recall denial but I guess my early reluctance to acknowledge that my condition will not change was a kind of denial. Anger I have not allowed myself to feel, though I have at times felt that the surgeon who prescribed the drug ought to apologize—a letter, a bouquet of flowers—something. I did have a dream in which my surgeon was talking to me, weeping. What I realize, too, is that acceptance is not once and for all. I think I have accepted my condition, then I go through a spell of kicking out at it, resenting it, and then I seem to accept it—not on a deeper level, it isn't a matter of depth—but on a more pragmatic level, as just part of the conditions on which I continue to live. Some people say I should sue the surgeon, but I gave written – though not informed—consent to treatment. Besides I am in no condition to cope with the stress of a law suit, and the outcome is always uncertain.

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August 10

 I just read an article by James Houston, the Canadian artist who went north in the nineteen fifties to promote Eskimo carving and who started Eskimo print-making. He says the Eskimos have a word, *iyonamut*, which means, “There’s no helping it. It can’t be changed.” *Iyonamut* isn’t a consolation. There is no consolation. It is just a statement of fact, the way things are. It says, implicitly, stop the fuss, pay attention to something else, something you can change. *Iyonamut*.

August 12

 This morning I remembered the lines from a hymn we sang as children:

*The harvest waves in the dewy morn
And the men go forth to reap
And fullness comes to the tasseled corn
Whether we wake or sleep
And far on the hills by feet untrod
There are blossoms that scent the air*

These lines give me a delicious, pristine, expanded sense of the assurance of beauty that one does not have to create or even know about. What a relief. I love the *farness*, the *distance*, and also the words which, by expressing *farness*, bring it near. I love to linger in that duplicity, that contradiction. “Far” means “far” but the word brings it near, into

one's eye, one's mouth. And I am solaced, especially now, when I feel so cut off, by the sense that the world can be trusted to proceed without my intervention or even my awareness, whether I wake or sleep.

August 15

 Last night M. took me for a long walk, across the foot-bridge where Haywood Street goes over the creek. I often used to walk to my village that way. We saw a regal sunflower and I noticed that the salal and blackberries are ripe—reassuring seasonal change. I did pick half a pail of blackberries the other morning in our lane, but I cannot reach the high ones.

I told her how I feel about my body now: as if I were brain-damaged or as if I have been put together in a laboratory by someone who did not know how to do it. I lurch, and lurch again, as I laboriously lift up one foot, put it down, lift up the other, put it down. I feel as though I ought to roar and howl, like some monster, like the Wolf Boy or the Elephant Man. I feel, too, as if the monster hidden in me since I was a child has taken over my body. I feel obscurely punished. She reassures me, “You don’t look like a monster.”

When I came home I wrote a draft of a poem I called “*Damaged*” in which I tried to express how I feel about this new way of seeing, moving, and that gave me the feeling of relief, like a weight lifting, that writing a poem often gives.

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Perhaps it was writing this poem, confiding to M. my deep sense of being damaged, and managing a walk of that length, within sight of the village, but I feel slightly different now. I no longer feel like an impaired person, but rather like a normal person with a marginal impairment. Something has shifted. Instead of being central, the most important thing about me, my disability seems incidental, not an obstacle looming in my way, but a constraint, simply that. I no longer indulge in fantasies of extreme situations, scenarios of flight at night, in which I would be a burden, an impediment, a trouble to everyone. The things I shall never do again, like swimming in the sea, canoeing, going out alone after dark, are so simply out of bounds that I do not even allow myself to regret them.

August 18

 I had the second set of ENG tests today, this time with only ice water. There was no measurable response. I just felt coldness. So there is no balance function left at all. The destruction, I am told, must have been catastrophic, sudden. Gentamicin induces processes in the hair cells that cause them to destroy themselves. Millions of follicles self-destructed. I feel sorry for the little follicles, which I imagine as diaphanous, waving, delicate creatures. There is, however, something final, satisfying, in having them completely gone. It is an end situation, stable, and therefore a place to start from.

August 19

 Now when I wake in the morning I find myself not imagining coping maps for walking but rather writing in my head the story I am working on. Such joy to be unstuck from my ordeal, no longer mentally rooted to it, oppressed by it, but free to let my mind turn to other things.

August 20

 I feel great excitement going to the art gallery in the city. My first bus ride since I became ill, but it was easy, with a companion, even stepping on and off. It was wonderful to mingle with people, to be out in the world. My only difficulty was in the large galleries. The spaces seemed dizzying, the distances from wall to wall enormous and disorienting. Still, I managed well, walking alone near walls (remembering not to touch the paintings) and crossing spaces with help. Art has always been for me an unflinching consolation, because it plucks me out, or rather it leaves me where I am, on this spot, in this damaged body, but gazing at something beautiful which has been made by somebody also trapped in a body, perhaps as impaired as mine, or more so, yet capable of making this beautiful thing. These works, by the Canadian painter Paterson Ewen, are heroic, huge: meteorological and cosmic images painted on wooden panels and then gouged out with a power tool. I find them beautiful and brave in their linking

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of the maker—and the viewer—to the vast, mysterious and sheltering world. They are both lyrical and strong, daring, enormous images, but never losing the poignancy of their being made by a human hand, out of the human eye and imagination. He paints abstract patterns – meteorological maps and charts—together with stylized renderings of lightning, rain. He expresses the cosmic wonder of being here on the Earth.

August 21

 Made bold by the excursion to the art gallery, I started out alone this morning, managed to walk to the end of the lane and across 14th Street and then could not go any farther but was rooted to the spot. Distances seemed enormous, vistas intimidating. Cars passed by and I clung to a tree. If I looked downhill I felt I would fall over. I wanted to sit down on the ground and crawl home. This seems regressive, but my impulse now when I realize I cannot cover a distance by walking is to get down on my hands and knees. I stood immobile, holding on to the tree. Then someone walked by and I asked him to walk me back across the street to the edge of the lane behind my house. Once there, I can cling to vines like Tarzan and weave my way up the garden and into the house.

I half guiltily order books. Mail order had been a solace for me since I was a child and my sister and I pored over the mail order catalogue, then waited for what we had ordered

to arrive. A brown-paper-wrapped parcel in the mail is still one of my greatest pleasures. If I cannot go out into the world, I can summon bits of it to come to my door. Now I have sent for, at great cost, in my impoverished state, *The World of the Shining Prince* by Ivan Morris, and a translation of *The Sarashina Diary*, from the same period as *The Tale of Genji*. This world, Heian Japan ten centuries ago, is a place where I can live with complete satisfaction in imagination. I feel mysteriously akin to the women who wrote these texts. These women, a thousand years ago, lived in seclusion, constructing a world from hints, rumours, images, overheard sounds, and they honoured the flow of seasons, the weather of emotions. At the moment, in my confined world, I feel rather like them. Women in these accounts were rarely completely seen except by their servants, relatives and intimates. Otherwise, they were seen through the tropes of synecdoche, metonymy: a forehead seen over a fan, the edge of a robe glimpsed under a curtain of state, a sleeve worn fashionably long enough to hang out the window of an ox cart as it rumbled through the street.

The phrase Ivan Morris uses to describe the attitude cultivated by this society toward the known world, life, time, is *mono no aware*, which is, he says, close to our phrase *lachrimae rerum* (the tears of things), but not so intense. It encapsulates a cluster of feelings: awareness of the transience of things along with their beauty, one's unworthiness together with one's good fortune to notice beauty—and one's obligation to notice it, for to observe beauty is the goal and point of existence, of what it means to be human. So the aesthetic becomes the ethical, a way of living, a code of conduct. Yeats says somewhere that he is in

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love with what vanishes. The De La Mare poem I memorized as a child and still recite to myself says “*Look thy last on all things lovely / Every hour*” but that has a hint of tension, of urgency, that is absent from *mono no aware*. Still, how lovely the last lines are:

*Since that all things thou wouldst praise
Beauty took from those who loved them
In other days.*

Well, that is how I want to live —and can.

August 22

 Very wobbly today. Everything shifting. Reading Annie Dillard’s essays. “Go for the throat” she says. Why would one ever go for anything else? Life presses us to its edges and some elixir, some essence is squeezed out. Reading old diaries about my divorce, I find that trauma of anguish and separation distant and almost trivial now, like a narrative I once read. New traumas have shaken me, call for my attention.

I have decided: I cannot work this fall. I can’t even walk to the bus stop, so how could I, in a few weeks, commute by two busses to the college? Since the semester begins in three weeks, and I have to give the college time to find a replacement, I shall phone soon to tell them. How shall I manage, financially? I have the \$400 a month from my ex-husband,

the rent for the garden suite, a small sum from unemployment insurance, and in a crisis my credit line, because, thank heavens, I own my house. And I have my home tutoring, which I can do sitting still. I'll try to get more students. But I shall have to be very careful with money, hope the furnace doesn't break down. So be it. *Iyonamut.*

I listen to news on the radio and remember what Wallace Stevens says: the imagination must resist the pressure of the world, of history, which presses with such force and violence on us, here, now, by exerting a counter-pressure. And the counter-pressure has to be active: to imagine the real, to make something beautiful or useful here and now – a story, a poem, a picture, a child's toy, a nourishing meal, a garden. Yet I live in this paradise of late summer, my porch overlooking the garden, the ocean in the distance. Reported violence elsewhere seems far away.

August 23

 If you pay attention, life brings you what you need. Something timely was given to me last night when I watched a video of the movie *My Life as a Dog*. In this film, a small boy whose life has fallen apart with the illness and absence of his mother comforts himself by contemplating the woes of others. He collects stories of distress to make himself feel lucky, blessed. His refrain is "You have to compare." He says, "Things could be so much worse; terrible things happen to people all the time." The worst thing he

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hears of is the plight of the little dog, Laika, the Russians sent up in a space capsule, who will die alone in space. Near the end of the film, told that his mother is dead, he locks himself in a summer house, barking at the windows. He has reached his extremity and has 'become' the little dog trapped in the space capsule. The images of the child barking, enclosed, made me cry. I would like to bark, to rail. He is comforted by a mug of chocolate and an embrace. There is no nonsense in this film about 'grief' or 'healing', no attempt to counsel the little boy, to give him 'therapy.' I love this little boy and what he taught me: you have to compare, but also acknowledge your own loss.

August 24

 I finally phoned the college and said I could not teach my two courses this fall. When I briefly told the English convener what had happened to me, he was sympathetic and I began to feel a little sorry for myself. I recalled the lines from *Lear*, "*I should e'en weep, to see another so.*" Perhaps it is just as well that we do not see ourselves but experience ourselves as it were sheltered, from inside. I had been looking forward to working, to earning money again. But now I am relieved. I was dreading the effort. I am always afraid of giving up too easily, not trying hard enough. But I have not yet been out alone; how could I commute by bus to the college in two weeks? Had I known at the outset of this ordeal that it would take me this long to adjust this

far, I might not have been so cheerful. Now I am patient.
Iyonamut.

August 25

 Leaving D's last night at dusk, though I was with friends, I was disoriented by shadows, very unsteady. I must get a flashlight. It will soon be September. The days will draw in and I shall be confined to my house. I can never again go out alone after dark. This sense of the night world as not traversible, as confining, must be there in our bones, from ancient days when the only light was from stars or moon and a torch. Or so I tell myself, as a way of incorporating my new condition into something familiar.

Yesterday I walked with A. in the early afternoon to pick blackberries. The sun glared. Cars rushed by and I could scarcely stay on the sidewalk, distracted by their noise and movement, every step deliberate and precarious, harsh shadows distorting surfaces. The landscape swimming, I totter and lurch. The effort is unnerving. I perceive that I am impaired forever. We managed to pick a pail of berries to freeze. Making jelly is beyond my capacities just now.

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August 27

 Still I have not gone out alone yet, and it is almost two months since my condition was diagnosed. But M. has a good plan: I am to meet her half way to the village. I shall walk a few blocks down the hill at an appointed time, keeping as close to fences as I am able, knowing that she is coming to meet me and that if I get stuck and can go no further, she will soon come to rescue me. If I do not arrive she will just keep walking up hill until she finds me, and if I am stock-still, she will understand and then we will walk down together.

When someone is alone as much as I am, the renewal of feeling becomes a problem. I remember when I first lived alone, a few years after my divorce, after my children moved out, my sense of the boundaries of my body became vague, and I realized the truth of what is said about new-born babies: the only way they can gain a sense of their shape is through touch. It has to be tactile. But I gradually got used to living in my house alone, began in fact to like being alone, like having various rooms at my disposal. But how to renew feeling? Virginia Woolf and her friends kept falling in love, but their world was peopled enough to make that possible. Once I am more independent, able to go about the world on my own, I shall not feel so depleted. As soon as someone comes, I am animated, I sparkle, but after they leave I feel—what?—like a snail that has withdrawn into its shell. Yet the presence of someone else in my house leaves a kind of residual echo, a trace of liveliness.

August 29

 I still need about ten hours sleep a night to feel alert in the morning, but I love dreaming and have recorded many vivid dreams in my Dream Book, so sleep is not wasted. And it is said that healing takes place during sleep. I love the time between sleep and waking, when my mind, still fluid, floats, not yet fixed on anything. This is a creative time. Images for writing occur, or sudden solutions to small problems, or even memories of where I have mislaid a book. The notion that one should spring out of bed and confront the day may be fine for some, or for those who must, but for writers the drifting interface between dreaming and being awake is a resource.

In my house, now, except for the swirling and bobbing of things, and except for stairs, I function almost normally. My foot-work has really developed. Indoors I walk bare-foot for the most part and make without thinking complex patterns of small steps when I am turning, and my foot grip on the floor is very strong, my toes slightly curled under. A. tells me that this is how Sumo wrestlers stand upright in spite of their bulk and even when pushed: their foot-grip. But anything unexpected underfoot, no matter how minute, almost topples me over.

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September 1

 J. came and drove me to her house for a change of scene. It was delightful: we sat on her lawn drinking iced tea. But the grass is uneven, the terrain hilly. It seems I have to relearn every territory, however familiar, with my feet and eyes. Again, this is a kind of gift, forcing me to pay attention and scrutinize places I mistakenly thought I knew, but now must learn in a different, tactile way.

D. drove over in the evening and took me walking along the sea-wall. A pleasure to be out sauntering with the people of my community in the warm late summer evening, hearing them chat about small things. I hear part of a narrative as people approach, going in the opposite direction, and as they move on, the story fades, unfinished. Sometimes I long to follow them, to hear the rest. By the time we walked back to her car it was dusk and I could see that I am enormously hampered after the light begins to fade. When D. left me to look for her car, I was unable to move and stood rooted to the spot for fear of falling. I looked for a lamp-post or a tree to cling to. I must remember to put my flashlight in my purse.

September 2

 N. was right when she said in a recent letter that we writers are very lucky: we are always able to turn to the world of intellect and imagination. What is true, too, is that the world is full of brave people who have secret,

undeclared difficulties, with which they cope courageously every day of their lives. J. says that since she has been worried about my condition, she looks with new compassion and interest at disabled people walking about New York. So I have unwittingly given her this gift of new empathy.

It is all very well to tell myself, "It could be worse, you are not so badly off," but the truth is that one's body remembers and wants to feel again the bliss of heedless functioning, and the psyche wants to be normal, to be healthy, to live in the world at ease. One of the things I love about Oliver Sacks' 'clinical fables' is the way in which his narratives honour the craving of the human organism to be whole, to feel normal, so denial is not pathological but can be a sign of the will to be intact, as the phantom limb provides a fantasy of remembered wholeness. I may not in the scale of loss have lost much, but it is not nothing to lose one's balance, permanently, so if occasionally I cry and feel a little desolate, I am perhaps mourning this loss, and the loss of the stable sense of the world I used to have.

But I was taught to be cheerful in affliction, and thereby help to redeem the world, and have long believed, with Keats, that the world, beautiful as it is, is a "vale of soul-making".

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September 3

 I avoid contact with people who do not know my condition, fear they may literally put me off balance or knock me over. Yet I like to be greeted, treated, as if I were normal. If anyone comes too close, I back away. I need to have a certain amount of space around me, need room to maneuver. I went with M. to a picnic in the park, happy to be with children effortlessly playing, and then a woman I scarcely know rushed at me so that I staggered, betrayed my weakness to her, and felt I had to tell my story. She said, "I know", her face contorted with sympathy. But she does not 'know' and I do not want her sympathy. Why should I have to confess my weakness to someone so overbearing? After I came home, I cried, weary and discouraged. It is the old grief: not to be seen, or to be seen in a distorted way, reduced to a cliché.

September 4

 I do adjust, in fits and starts. After discouragement comes a new level of acceptance. I think of Katharine Butler Hathaway, my friend and spiritual guide since I was sixteen and first read *The Little Locksmith*. Deformed by tuberculosis of the spine, she felt like an outcast from normal human life. When I first read her, at sixteen, some of her terrors were like mine, though mine were caused by my anorexia, which distorted my sense of self and cut me off from others and the world. I learned from her to control panic by looking

intently at some detail in the external world. I relate to her in a new way now: her fear of being perceived as disabled. I remember Kafka's saying that if you keep very still in your room and wait patiently, attentively, the dragon of reality will come and coil, docile, at your feet. Often I feel its presence, I believe it is already here; all I have to do is to learn to pay attention to it.

The trick is always to turn affliction into a blessing, to force the angel with whom you wrestle, to bless you. If that is possible. I am lucky: my affliction is light. And I am alive: people are so fragile; it is so easy to die. Now I begin to feel as though I am living through this new way of being in the world, so that it is no longer a burden but just the way I am and shall be. I must be close to a kind of acceptance. I read what Gillian Rose says in her memoir *Love's Work*, her account of a medical crisis that changed and threatened her life. She speaks of the life-saving work by which "*when something untoward happens, some trauma or damage, ... one makes the initially unwelcome event one's own inner occupation. ... In ill-health ... this is the hardest work: it requires taking in before letting be*" (90-91).

The temptation is to stay home, where I have the illusion of functioning well, and where I do not get so tired. Yet I must accept invitations to go out into the world, must reclaim the world as much as I am able. And all I have to do to refresh and restore my sense of the normal world is to lie on my chaise longue and watch the world be still.

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September 7

 It does not end, and why should it? I went to the village again with M., met her half way down the hill again by prior arrangement, and we had coffee in a cafe. I had planned this time to be left on my own in the village, but the sidewalks are being mended and are full of gaps I could not cross on my own. I stand on one side of a small crevice in the sidewalk and cannot think how to go about stepping over it. Then we went down to the beach to find stones for me to paint, and once off the boardwalk and on the pebbled beach I was incapable of walking on my own; I stumbled and leaned on her arm. When I got home, I was so fatigued with the effort of walking I had to lie down.

Blackberry picking with T. went well enough, but she was late getting here and by the time we finished picking, it was dusk, which comes earlier, now. I love the long shadows, the blackberries disappearing into the dark leaves until you cannot see what you are picking, but once the light faded, I was utterly disoriented. Then the world became a place of luring, shifting shapes and surfaces I could not see to place my feet on. I have to keep telling myself that I'm not brain-damaged, that rest and stillness will restore me, that I will gradually learn to function better.

Shall I have the courage to go out by myself next week? I secretly plan to do so. I'll do it as I do most chores that stare me in the face and frighten, repel or dare me: I'll slide into it, find myself doing it, taking the first step before I have taken thought to dream up discouragements. And the truth is, I'll probably never be much better than I am now. Yet, 'You have to compare.' In Africa, people die in massacres, of preventable diseases, starvation, and the venom of poisonous snakes.

September 8

 I still do not have my old stamina. My resources are almost depleted. If I sit at my word processor too long, I am almost ill with fatigue. If, in addition, I walk or do housework, I am done in and have to call the rest of the day off. Last night I sat on my porch after supper, surrounded by my cats, my familiar spirits, and cried with nervous exhaustion, the pent-up tension of the whole summer. I have tried to make light of all that has happened to me, to be stoical, as my mother taught me to be, and my weakness has to come out in some way. But, why do I feel so filled with grief? I feel like Job, or as I imagine Job felt. People say I walk well, now, but I still lurch and pitch about in an unstable world, exhausted most of the time. Is this a life? Yes, it is a life and these are its terms. *Iyonamut.*

And I do get things done. I put one or two stories on disks every week, I keep my house in order, I make phone calls. I think of the story of the knight who remained behind in the castle while the other knights went out to perform derring-do and attack dragons. The knight who stayed home had to guard the castle but he felt deprived of taking part in the exploits the other knights would perform. The sign of having vanquished a dangerous foe was a light on the forehead of the hero, who would then be acknowledged a true knight. While the others were out performing heroic gestures, the knight prevented a dwarf, an evil creature in disguise, from entering the castle. When the other knights returned from their adventures, they saw the

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light shining on the forehead of the one who stayed home. As a child I identified with that knight, and I do now, but I realize I want some sort of reward, want to be recognized, as the knight was.

Looking at my copy of *The Little Lame Prince*, a children's story about a crippled prince shut in a tower, I see again that he was rescued by imagination. The power of imagination is embodied in the travelling cloak given him by his fairy godmother, which looks like an old rag, a bit of rubbish, but is really the way to transform imprisonment. Sitting on it, he can float out the tower window and survey the whole world. So I try to use my imagination to make sense of the constraints of my condition.

I am powerless to do things myself and yet it is hard to get others to do them even if I am willing to pay. I phone repairmen, they promise to come, and fail to turn up. Then I feel helpless, hopeless. I write furiously in my journal while waiting for them to arrive or at least phone, but I cannot write over and over, "I am waiting, waiting." In the opera I went to the other night with M., a modern chamber opera adapted from a tale in *Gengi*, one of the characters sang 'a waiting song.' I should devise such a song for these occasions; turn a 'complaint' into a 'waiting song.' Then the waiting would become bearable because it would be singing, not waiting.

September 9

 Perhaps it is the fall, the beginning of school, of college, that depresses me, since I am not part of it. I always loved going back to school as a child. I disliked the shapelessness, the heat, the insects, of summer. School gave a pattern to the days and at school I was good at everything I had to do and there seemed to be endless supplies of paper, paint, books. Later as a teacher I loved the excitement of the new term beginning, a fresh start, an opportunity to do better. I was married in early September. Now I feel as if I am not part of anything, as if nothing much is in store for me.

I resolve once again to quell the spirit of negation in me: I say *retro me*. It is the 'nay-sayer', sucking me into the black hole of despair, haunting me with my failures. Is it my mother's voice, reminding me that to be less than perfect is to be nothing? The voice of our house-keeper when we were children, who instructed us to expect the worst, to believe that any small happiness would be, by a kind of cosmic necessity, balanced by some misery? "If you're laughing in the morning", she would warn, "you'll be crying before bedtime." Rather than hating myself for my anxieties, I should regard them as natural, look for their sources, and avoid the occasions that arouse them. And one must continue to feel, to express feeling; otherwise the world seems bleak, depleted of its vitality.

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September 10

 I have been reading another book by Christopher Nolan, *Dam-Burst of Dreams: poetry and aphorisms*, one of which is “All men mull over hell. Land lovers count their acres, moneyed folk count their millions but wise men count their cold, holy crosses. And that is the central core of our existence on this earth” (11). This horrifies me, and yet I mull over little hells of my own devising, like the torment of waiting for weeks for my garden chairs to be fixed, my powerlessness to do anything about it. I can’t bear not having them. I want them, want to fill the gap. I say to myself, “Cut your losses, buy two new ones” but I cannot give up the hope that they will eventually be fixed by the seemingly reliable but absolutely feckless man who took them away to repair. I try not to let my frame of mind be dependent on the actions of others, but I cannot get to that place.

The truth is I am too much alone and the world does not sufficiently exist for me because I do not go out into it. Our spirit has to wander forth into the world, but it helps if our body can go, too. Writing here is a kind of addiction, a drug, a substitute for living, and yet I must do it, lay some of my absurd burden down on these pages, between these blue lines.

Odd, or perhaps characteristically human, how we bargain with fate in our minds, indulge in “magical thinking”. I find dubious comfort in the thought that having endured two major operations in six months, I shall be spared another forever; the notion that since I have suffered one serious disability, I shall not be burdened with other catastrophes. Yet neither life nor literature gives any assurance that this is so, that one misery is an insurance against others.

September 11

 Well, I finally did it: I walked alone two blocks down the hill to the bus stop. I kept close to hedges, held on to fences, and trees. There is a sturdy post where the bus pulls in. I got on the bus, went to the shopping centre, did some errands and came home in a taxi. Now I feel different because I know that I can get about on my own. I am once more independent. It seems simple, now, to walk across a parking lot, keeping close to stationary cars and any other visible supports, and go into a store. By concentrating on the act of walking, I avoid staggering too much. My body has learned to do this. Now my disability can be pushed to the periphery. Soon I shall go to the city alone by bus. I needed help only once today. Or rather, I did not need it, I was just pausing over a slope on the sidewalk, deciding whether to negotiate it or to side-step onto the road, and a man came up, grasped my arm and helped me across the street. Thinking I owed him some explanation, I said, "I've been ill and I lost my balance."

People like to help. It makes them feel hearty, able-bodied, capable. I sometimes sense this attitude in the young, toward the old. I have sensed it in myself: a kind of superiority to age or infirmity which engenders a kindness that can deteriorate into condescension but which is natural, for all that. It is natural to rejoice in being hale, whole. What can be really unnerving is to encounter someone I have not seen for years. This happened the other day in a cafe. A woman came over to me and said, "I thought it was

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you, but could not be sure.” I knew her at once; she had not changed much. I fear, then, that I have changed—terrifying phrase—‘beyond recognition’.

I bought some new sturdy walking shoes, to improve my walk, and I bought a present for myself, for having struggled all summer: a blue ceramic urn with pale yellow dragons on it. Next spring I’ll put it on my porch with geraniums in it. How I loved going into the produce market, feasting on the abundance of fruits and vegetables. And how wonderful to get into a taxi and be driven home.

September 12

 I managed to do a little weeding in the rock garden. Once I get down on my hands and knees, I’m OK. It’s getting back on my feet that is difficult. The autumn crocuses are showing. I remember one fall trying to think of a “venereal term” for autumn crocuses, like an exaltation of larks, a murmuration of starlings. The one I came up with is “a haunting of crocuses”. They are like a ghost of spring. I love the sudden appearance of the large, pale mauve flowers, close to the earth, with no foliage.

September 13

 Returning to a more normal life has its irritations. As my world expands, so do my obligations. The list of things I can't do suddenly shrinks. After months of almost blank pages in my 'daybook' I now make little lists of errands, things that I 'must' do, and enjoy again the tiny rapture of crossing them out. When they are done, I ask myself, "Why should I, weak as I am, have obligations?" and reply, "Because it strengthens and normalizes me, to have them." So it goes on, another day the gods have thrown me, and if I am exhausted at the end of it, that means I have been able to exert myself to live.

One new ordeal is having to endure being seen in public, on the bus, on the street, by people who do not know what is the matter with me. Public transportation is just that: public. People can get into their cars in any condition, any clothes, barefoot, disheveled, but on the bus you are visible. Taking the bus to the college in the mornings I was always touched by the well groomed look of people going to work, the care they take with their persons as they begin their day. I was used to being public and visible on the bus, but now I worry whether I shall make it to the nearest seat without staggering. It is amusing and ironic when the bus driver says to me, as I prepare to step off the bus, "Watch your step!" If only he knew that I am constantly preoccupied with literally watching my steps.

I am still not emotionally stable. The doctor's office nurse spoke kindly to me on the phone, and after I hung up, I cried because of her kindness.

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September 15

 Yesterday I wondered if I would ever again feel that lifting of the heart, the spirit, that elan of life, and though I do not feel it yet, I sense its possibility; it hovers on the edge of things. When I went for my walk with L. this morning, I felt a new sensation, as though my feet have taken over. They are once again doing it, walking for me. I no longer have to concentrate with every step. My good body has learned this. The world stills swoops and wobbles, but it scarcely matters. It no longer much affects the way I move through it. The unstable visual field no longer distracts me, scarcely interests me. It is just the guise reality takes for now. And even though I see things shifting, swerving, I no longer perceive the motion as a property of the world. I know it is an illusion. I am firmly established in some centre of functioning that has become almost matter-of-course. I look down and there are my reliable feet, walking on their own, without my taking thought, independent of my looking at them. If I lurch and stagger from time to time, if I pause at thresholds which indicate change of elevation, of texture, I am grateful, the next instant, that I am still erect and moving.

Having read poetry all my life brings its own particular pleasure and handy solace: often I can tell what my mood is, especially on waking, by listening to whatever fragment of poetry is in my mind. This morning I awoke thinking of the hymn

*I feel the winds of God today,
Today my sails I lift
Though trembling oft with heavy spray
And torn with many a rift.*

I take this as a good omen: even though my sails are torn, I can lift them and venture forth. Often this summer I have recited to myself the lines from Edmund Waller's last poem:

*The soul's dark cottage,
Battered and decayed
Lets in new light
Through chinks which time has made.*

September 20

 Each person copes with what life brings in a way that expresses his or her whole character. I realize that my resolve—a reflex, really—to make the best of things, allows little time for acknowledgment of loss. I have responded in this way as long as I can remember. Is it because there was no consolation available, that I could not admit grief? I recall my sister and I mutually confessing just a few years ago that we both, if we can afford it, buy two of anything we like, so that if the thing purchased gets lost or broken, it can be instantly replaced; thus the moment during which loss is admitted and must be endured is reduced to a sliver of time so small it scarcely allows room for mourning. So I live in this fashion.

Well, would it be better if I raged, tore my hair, immobilized myself with grief? What would be gained? At least I minimize the suffering of others and maximize my own functioning.

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For weeks after losing my balance, I was normal in dreams. There seems to be a certain time lag in dreams. Now, alas, I am for the most part impaired in dreams, sometimes perilously making my way down damaged stairs, over broken bridges. This is the metonymy of dreams: the damage done to me is projected onto a damaged thing.

September 24

 Sometimes I daydream that I will be miraculously cured, that the normal world, a normal body, will be handed back to me: take up your bed and walk. That I shall wake up some morning, get out of bed and walk normally down the hall. Now I understand why the afflicted, whose company I have marginally joined, go to shrines, touch saints' robes, crawl up cathedral stairs, hoping for a miracle. My disability has made me a member of the honorable company of the majority of mankind, who experience life as an ordeal. And yet, and yet, something in me objects to the notion of impairment as the norm. It isn't, it can't be the norm. The body and spirit crave wholeness, strength, the joy of function.

I have always been drawn to figures in literature and life who represent those who can't quite make it in conventional terms, who have no chance of being one of the beautiful people. The prototype is the *Jongleur de Notre Dame*, who was hopeless at even the most mundane tasks; all he could do was juggle. The end of the tale is that his

juggling is found to be an acceptable offering to Our Lady. Do I glorify my state by thinking of myself as God's lurch, God's stumble-bum? Well, not if to think thus helps me to integrate my condition into a productive life, and not unless such a metaphor glorifies me above others. In a sense we are, each one of us, what we are, for God's sake, whatever we take that to mean

One thing I do regret is that perceiving the world as I do isolates me from others who see the world normally. It is as though I now carry with me more palpably than most others a world which is fractured. Is this a double affliction, to be impaired in a world which seems dislocated? The truth is, the world has not changed, only my perception of it. True, my ability to function has changed, deteriorated. But when I am still, the world is restored to me. And as my sister said at the beginning of this ordeal, there are those who walk about the world with normal-seeming bodies and impaired souls.

October 1

 Just when I congratulate myself on 'passing' as if I were normal, I forget how soon darkness comes on, now in early November, and the other day I got on the bus too late to reach my door before dark. I watched with dismay the growing darkness outside the window of the bus and wondered if I would have to crawl across the road and walk home clinging to fences and trees as I did when first

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impaired. Fortunately I recognized a neighbour who also got off at my stop. I briefly explained my odd predicament to him and he walked me home.

I don't understand why night walking is so difficult. The limiting of peripheral vision by the dark ought to be a help, not a hindrance, but that is not so. I am no longer conscious in daylight of using my eyes to balance myself—except for looking at my feet on stairs and slopes. My eyes give me false information: they tell me that the world is shifting and wobbling and what my feet have to do is to ignore these messages, to move as if the world is stable, as it proves to be when I step on it, for the most part. If I step on something that looks stable and proves to be slippery or soft I feel as if I have fallen into an abyss. Yet in the dark the world becomes radically unstable, almost fluid.

October 4

 I have still to work on my sense of myself: first, my feeling that my impairment is the defining and the most interesting thing about me, the thing that makes me noteworthy, fascinating, a kind of walking statistic, embodying a rare iatrogenic condition; second, the feeling that I am somehow diminished, that people will shrink from me as they shrink from deformity. As usual, these two attitudes are contradictory. One says that I am attractive, albeit in a perverse way, the other, that I am repellent. In fact, neither is true. Most people most of the time are not aware that I

am impaired, and are so preoccupied with their own lives that they do not care.

The other day as I walked to M's house in a light rain, day-dreaming, not bothering to control my walk, not concentrating on walking straight, a car passed me, stopped, and a woman got out and walked back toward me. At first I thought she wanted to ask me directions, but she put her arm around me, solicitous, asking, "Are you ill? Do you live near by? Can I give you a ride anywhere? Are you sure you're all right?" My daydream shattered and I felt conspicuously disabled. I explained that I had lost my balance but could manage and was otherwise normal and in good health. I was unnerved by her intervention and staggered even more as she drove away. Perhaps she thought I was drunk. But I realize, too, that if I look impaired I give others an opportunity to express their concern and kindness.

October 7

 I wonder again if my condition is a purely modern complaint. Did anyone before the twentieth century experience the world in this way? Or is the destruction of balance dependent on the intricate ways in which modern medicine penetrates the body and its systems, most often with benign and beneficial results but now and then, as in my case, and the cases of others like me, with catastrophic side-effects?

One sometimes embarrassing social consequence of

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my condition is that I cannot recognize even familiar faces if people approach me while I am walking. They are full upon me or sometimes past, before I can focus on them and identify them.

Moving from light to shadow is difficult. I have to pause at the edge of a shadow and reorient myself. A well defined path, like a sidewalk, helps me to walk straight. What I like best, walking, is to be near a wall or a fence that I can touch lightly, not too obviously. Then some of the effort to walk straight is given over to the support.

October 9

 Feeling very damaged today, even in my house, very aware of things tilting and wobbling. Heavy rain. Perhaps it is the diminished light, after the intense light of late summer.

One challenge for me, a writer, is to find words to describe how it feels to be me, now. I say “it” because it is a matter of something both inside and seemingly outside of me. The way I experience the world when I move is outside normal perception. People sometimes ask, “Are you dizzy?” and I reply, “No, in fact I’ll never be dizzy again, since dizziness is a dysfunction of a normal balance system.” There is no way, no word, for describing the peculiar disorientation imposed by this condition. It is as if some invisible force behind the phenomenal veil of the world were shaking it.

October 11

 I think: this is forever, this new way of being. How I manage depends on light, on whether I'm tired, whether I am upset, whether there are railings. I have become acutely aware of structures, especially stairways. If there is no railing, I can walk up stairs only by stooping and touching each stair, and I am unable to walk down without assistance. I can use up-escalators because I can somehow get a visual fix on them, but not down-escalators, because, when I walk down ordinary stairs, the stairs seem to be shifting and moving, and escalator stairs are actually moving, so I cannot sort them out safely and put my foot on the top. Now I understand why access to buildings for the disabled—ramps, wide automatic doors—is so important. If such facilities are not in place, the disabled, of which I am now marginally one, are in effect shut out.

Spells of well-being, the triumph of managing, alternate with spells of this feeling I can find no words to describe. Fatigue, impending illness, bring back the macabre sense of disorientation I felt at first.— as if the veil of Maya, the veil of illusion, has been ripped and I have to walk through it. Sometimes I would like a place, a diary within a diary, where I could howl and mumble, cry and get at the kernel of distress which I feel every time I move about. I must perpetually, daily, refrain from noticing the abnormal appearance of the world, and focus on the concentration needed to get about in it.

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October 14

 Interesting to read in the morning paper a report about human locomotion and the inner ear. It seems scientists have a new way of telling when the ancestors of human beings first started walking: by looking in their ears. The inner-ear mechanisms that provide a sense of balance are a clue to the mode of walking. *Homo erectus*, which evolved into the modern human type 100,000 years ago, was the first primate to walk exclusively upright. Human locomotor behaviour makes particular demands on the balance mechanism, for it involves the maintenance of an upright body posture by balancing on very small areas of support—two feet. Thus human beings, who always walk upright, have inner-ear configurations different from those of other primates. So I have become a throw-back; I have regressed on the evolutionary scale. I think of the Laurie Anderson song:

*You're walking. And you don't always realize it,
But you're always falling.
With each step, you fall forward slightly,
And then catch yourself from falling.
Over and over, you're falling
And then catching yourself from falling.*

The truth is, some of my behaviors and impulses have become simian. I curl my feet to get a better grip on surfaces; I reach out for support with my—fortunately—long arms. When sitting on the floor, I achieve a standing posture by putting my hands on the floor and keeping them there while I straighten my legs and raise my torso. Such

adjustments to my condition are spontaneous. I do what seems possible. When trapped by darkness, my impulse is to get down on my hands and knees.

I am still full of misgivings when I meet someone new, expect to be rejected because of my abnormality. I resolve to put my best foot forward and not to be a stone, a stumbling-block in my own path, not to set up artificial obstacles between me and others, not to use my difficulties, as I call them, as an excuse for not reaching out to people. I recall Samuel Beckett's words, "Tried. Failed. Try again, fail better"

October 16

 Darkness and possible snow remain obstacles. I feel trapped indoors at night. The darkness seems and for me is impenetrable. I plan ways of getting to the college in the new year if it snows. Thank goodness I live on this coast, where it usually rains, even in winter. But it is interesting to observe that if something is literally impossible, like walking alone in the dark or walking on snow, I simply accept that. Darkness falls and the world becomes unavailable. Being driven in a car at night has a kind of wild excitement about it: the forbidden.

And I clearly must avoid malls, crowds. The literally moving scene is too unnerving for me. I cannot focus on anything unless I am absolutely still, and I am utterly fatigued by the shifting glare of things. But I love going into

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markets. There I have a grocery cart to keep me stable. I am dazzled by the profusion and beauty of provisions, especially the produce counters and stalls, the colours of oranges, apples, spinach, carrots, the ease of people strolling about, the blessed company of those who walk without paying attention to walking.

October 18

 Writing a journal is both a removal of oneself from experience and a mastery of it. The writing self is displaced outside of pain, anxiety, so that the pain, the anxiety do not consume the self, as long as there is a margin of strength for the hand to pick up the pen. Writing also paradoxically establishes the interval of pain or anxiety, as not outside, not a brutal and frightening interruption, but part of the continuity of life, because it can be included in the account of life. Rilke says, somewhere, “*I have taken action against fear. I have sat all night and written.*” Andrei Sinyavsky says “*A sheet of paper is for me what the forest is to a man on the run*” (121) and “*One must know how to twine rope out of a phrase. And then walk on it as on a tight-rope. In the air. Without holding on to anything. Outside one’s own body*” (132). So I write the doldrums out of me onto these pages.

October 20

 One of the gifts public transportation hands me: bus stop conversations. Today, sitting on a bench at a bus stop, so that I seemed normal, I talked to a large Scottish woman, who cheerfully told me what can only be called a tale of woe—that lovely word for misfortune. One daughter with *lupus*, another with cancer, a husband who, she told me, “turned homosexual” and left her with two daughters to bring up. Her parting words as the bus drew up: “Well, dear, the good Lord doesn’t send us more than we can bear.”

I felt, as I often do in chance encounters, that I had been given some unasked-for wisdom. She didn’t say we have to enjoy what “the good Lord sends us” or even that it’s good for us, but only that we are able to bear it.

October 25

 Watching on TV an interview with the old American poet Stanley Kunitz. He quotes from one of his poems, “*How shall the heart be reconciled / to its feast of losses?*” It is useful now, with the loss of my balance function, to think of losses as a “feast”, not a depletion but a resource. He quotes from another of his poems, “*I am not done with my changes.*” Neither am I. My present and on-going difficulties are an opportunity to change, a sign that I, too, am not done with my changes. I think again of Rilke’s lines, “*there is no place / That does not see you. You must change your life.*”

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In another poem he writes of a year “*of anguish and vision and prayer.*” The year of my divorce was such a year, and this year has been another – decisive, demanding, a year in which life picks you up in its teeth, tosses you about, sets you down, and you have to redefine yourself, get your bearings anew.

I try to clear away the rubble of my life to get at something I can write about, work with. But perhaps it is the rubble that is my material. If I patiently practise writing, perhaps I shall be visited by some wonderful novelty. What Annie Dillard says about schedule is true: it is a net to catch the day in. William Stafford says that anyone can always write, though not always up to the standard of the person she likes to think she is. He says, “*Lower your standards and write,*” as I do in this book, grateful to draw breath and clutch my pen. It is like the space between high and low tide—no seasons here, but the perpetual transformations of the imagination wrought on what is there, as the waves moving up and back on the shore work on what is there.

October 29

 The truth is I still feel like an outcast in disguise, when I go out at night to any gathering, like the lecture last night, to which a friend kindly took me. I am anxiously concerned about my location, about direction, obstacles, exits, stairs. I avoid having people near me, fearing that, indoors, I might have to figure out how to get around them.

This makes conversation difficult.

I still feel abnormal all the time unless I sit and keep my head still, or stand still. I know it is caused by a lack in me, yet it still seems like an attribute of the world as well as a condition of my body. It is outside normal experience, a distortion, a skewing of things. I want it to stop but it will not stop. If I am perfectly still, I feel normal. The slightest movement and the world veers and whirls. Yet I resolve to try to think of myself as normal, not damaged; otherwise I add self-insult to real injury, and complicate my relations with people, the world. I have to accept not some version of my life as it might ideally be—a fantasy, anyway—but my life as it is. Embrace life, on the terms offered: *amor fati*. That's what it means. My life is confined in new ways, but that makes me resourceful and enables me to focus my energies.

November 1

 My bodily state summons up memories. I remembered today my father, late in his illness, shuffling as he walked – the mincing, syphilitic gait seldom seen now, even among the down-and-out. How I dreaded seeing him walk, on the rare occasions when I saw him at all. Why? Because walking is public, it reveals. It can be seen and judged. I remember seeing when I was a child the wife of the man who played the organ in the Anglican Church. She lurched wildly, could barely control her limbs. She was sometimes

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thought to be crazy, so tempting is it to link body and mind. Our mother told my sister and me that she was ill, could not help her condition and did not deserve to be ridiculed. Moreover, she and her husband were cultured people who commanded our respect. Now I think of her as I try to control my walk in public, and I remember how I was taught to value not outward appearance but accomplishments, bravery – the essence.

November 3

 When I was young I read philosophy, poring over tomes to try to make some sense of the universe and my place in it. I was like the young man who speaks the stanzas of the *Rubaiyat* of Omar Khayyam, which I also read when young:

*Myself when young did eagerly frequent
Doctor and Saint and heard great argument
About it and about: but evermore
Came out by that same Door which in I went.*

I have pretty well stopped reading philosophy but poetry is still my daily bread. I wonder, now, how the philosophers of being would have written if they had walked about in a perpetually shifting world. What if the so-called “peripatetic philosophers,” who philosophized while walking, had walked through the swerving, teetering landscape I see

when I walk? I think they would have been less certain in their statements about the nature of things. Who knows? They might have devised a whole system of philosophy based on the perceived difference between how things look when one is moving and how things look when one is still.

November 5

 Andrei Sinyavsky writes about the state of calm that comes when one really accepts that circumstances will not change:

But once you are over the dividing line, plunged into a situation in which . . . there is no turning back, no chance of escaping or trimming your sails, then the wholeness of an existence that neither threatens further loss nor holds out hope of gain envelops you in a feeling of serene and trusting calm (40).

I keep thinking I have reached this state and then I find myself overwhelmed again by minding, by wishing I were normal. I must remember, “You have to compare” and beyond that remember that many people live lives of private, daily heroism, and that to join this company, even in a marginal way, is to be fully human.

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November 7

 Rereading parts of my journal written before my balance was destroyed, I realize that my characteristic attitude toward life, the future, is to see it as a series of wonders and novelties, as the hymn I love says, “*I know not what the future holds / Of marvel or surprise.*” Yet I also agree with the epigraph to Dylan Thomas’s poems in which he quotes an old man as saying “*Isn’t life a terrible thing, thank God.*” It seems like an oxymoron to thank God that life is terrible but what the old man means is that it is a good thing that life is out of our control. One of the disturbing effects of gentamicin poisoning is that the person so affected seems to exert a weird control over the appearance of the world: I move, it moves. I am still, it is still. This goes against our reassuring, learned sense that the things around us, what we call ‘the world’ can be relied on to be what it is, not subject to our gestures, our locomotion.

November 9

 Writing constitutes my small triumph over circumstances. Often I feel scarcely fit to cope at all, except in the safe confines of my house. The physical stress, because of my lack of balance and the effort of control, has made me thin-skinned. Sometimes I feel like a tiny lantern fish, deep down in mire. Still, a lantern fish has a light, doesn’t it? I must not get in my own light.

I think of the Francis Thompson poem,

*When so sad thou canst not sadder
Cry, and upon thy so sore loss
Shall shine the traffic of Jacob's ladder
Pitched between heaven and Charing Cross.*

My 'sore loss' of balance has become habitual, no longer a fresh grief. This poem and others have kept faith with me from childhood and will always be there, in my mind, an available resource. My plunge into a strange world in which I could for a time no longer find my way, has come to a kind of plateau. As long as my life lasts, I shall live inside the changed world I began to inhabit when my balance was taken from me by gentamicin but I am used to it now, its features are not so sharp and intrusive. I think of Robert Frost's question at the end of one of his sonnets, "*what to do with a diminished thing?*" My perpetual effort is to think of myself not as diminished, but rather as granted an unusual perspective which gives me a new way of understanding what it means to be alive, to make a feast of my loss.

Postscript

A few years later. It is summer and M. and I drive to the Caulfield Rocks so that she can swim in the ocean. I won't be swimming because I can't manage to get myself from land to water, can't move in water unless it is still. Before we reach the rocks we walk through a path in the woods, sloping, with roots and stones underfoot, fallen branches to climb over. I could not possibly walk this alone, but M. takes me by the hand—sometimes both hands—and I find a foothold and stagger on. It is good to feel this uneven, natural ground underfoot. There is an absurd but very human heroism in this scene—and the ordeal is worth it: to sit on the rocks and watch the idyllic scene of swimmers, dogs, the occasional small boat. The achievement of getting there enhances the happiness of being there.

From Isolation to Community

It is now some sixteen years since I was damaged by gentamicin. I live in the same unstable-seeming world that descended on me after gentamicin coursed through my blood stream and destroyed the follicles in my inner ears. The difference lies in my adjustment to it. I still walk through a landscape that sways, jiggles and swoops as I move, but I no longer view the shifting scene as a property of reality; I know at some deep level that it is an illusion. At first, it seemed thick, real; now it seems thin, a surface phantasm. Long practice and strengthening exercises have helped. Fatigue, anxiety, illness bring back the stagger and disorientation. Darkness is still a swirling chaos. The slightest alteration in the surface under my feet can unnerve me and set me off balance. But this is how I thankfully live.

A few years ago a friend phoned me in excitement and said, "Turn on the television; there's a show about what's wrong with you." The camera, she said, showed an image of a room tilting and shifting. It was a short documentary about Lynn Brown, a fellow gentamicin victim and founder of *Wobblers Anonymous*, the Web site and e-mail network she established after being damaged by gentamicin. This is what she modestly says on the Wobblers website about her initiative, which has provided community, information and resources for hundreds of other wobblers:

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After one year of crying and feeling like my life was over, I started communicating with others damaged like me. I now have almost 600 people (friends) in a little support group and together we are trying to face the future. Each of us has had to start over, learning to walk and stand, adjusting to the dancing images we see when we are in motion.

Thanks to her initiative I and others damaged by gentamicin can, through e-mail, talk to and listen to others who live in the world as we do. Living without a balance system is so bizarre that it is very hard to explain to those with normal balance functions. Hence it is very isolating. Through the wobblers' network, all of us damaged by gentamicin can exchange impressions, experiences, anecdotes, with people who experience the world, daily, as we do. We never have to explain it to one another. What a relief to say "we", not "I".

Some of us are old wobblers, we have adjusted pretty well. We can sympathize with the dismay of the newly damaged, understand when they say it is a miracle just to walk across a room without holding on to something, and encourage them to keep trying. They too will get used to this new view of the world, and be able to function better as time goes on. We exchange medical histories as well as anecdotes about the strange and funny predicaments we get into. We talk about supports – canes, walking sticks, wheeled walkers, three wheeled bikes—about good days and bad days, good doctors and bad ones, triumphs and setbacks. Each one of us knows we belong to a group of people who, thanks to a modern drug, have regressed to a stage in human evolution before the balance function was

developed in the intricacies of the inner ear, to stabilize the image on the retina when the perceiver moves. Now, thanks to another modern invention, and thanks to the determination and hard work of Lynn Brown, we can get in touch with and help one another with encouragement, advice, information. Most of us live in the USA or Canada, but we have members in England, Australia, and Europe. Every morning when I open my computer I check my e-mail from my wobbler friends. I am no longer alone in the strange world I entered when gentamicin entered my body and changed my life.

I have learned much from other wobblers about courage and resourcefulness, about counting one's blessings and never giving up. I have learned that there are now available sets of exercises specifically designed to help wobblers compensate for their lack of balance. There are physicians and physiotherapists who have specialized knowledge about the human balance system and how patients can be helped to relearn to function without it. There are Web sites dedicated to this lore. The destruction of one's balance system, which usually happens suddenly, is dramatically unnerving and disorienting, especially when one is told, as I was, to just go home and get used to it. The development of resources to help wobblers adjust to their new condition is a step toward recognition of their plight and perhaps toward eventually reconsidering the use of the medication that caused it.

From fellow wobblers I have learned new ways of expressing what it is like to live in the world as we do, outside the norms of stable perception people take for granted, because they are granted, part of the exquisite adjustment to the world of a two-legged, erect creature who both sees

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and moves. Only when this ability to retain a stable image of the world while moving has been taken away do we realize how remarkable it was. All of us wobblers have puzzled over how to describe our condition to those who still move through a stable world.

One wobbler, a retired pastor, tells about preaching a sermon grabbing onto the pulpit and watching the congregation and pews swim before him. It felt, he says, like being on a large ship at sea in a storm and hanging onto a rail. When he tried to read his text, the movement of his mouth caused the print in the Bible to vibrate so he was unable to see what he was reading.

Another describes the world as she sees it as like a videotape taken by someone running on uneven ground.

Another says that in the early days after gentamicin damage she seemed to feel the whole world spinning on its axis. She felt she might be swallowed up by the vortex formed by the spinning.

Another comments that he feels as if he has been inebriated for almost ten years.

Another notes how when she puts on a new pair of shoes, she feels that the earth under her feet has changed and she has to readjust.

Another describes feeling as if his upper body is full of water and with each step, the water sloshes like a giant wave and he has to fight to keep the weight of it from knocking him down.

We share information, especially Web sites about gentamicin damage. Some wobblers are actively lobbying to have gentamicin taken off the list of allowable medications, or at least given to patients with clear warnings of possible

side-effects. Most of us were not told beforehand about the damage gentamicin might do. We all agree that our lives have been forever changed by the destruction of our balance system. We all encourage one another to live abundantly within the constraints imposed on us when the tiny follicles in our inner ears curled up and died, and we began our adjustment to a world we could suddenly not seem to depend on, a world which seemed to mimic us and move as we moved, instead of remaining still, obeying its own laws of motion for us to rely on and move through. The world's still here, and we're in it and able to put one foot in front of another on our own or with support, so we continue to make our claim on it.

Would we rather not be damaged? Of course. But there's no going back. Hair follicles do not regenerate. When I reread the journal in which I recorded the early days of my adjustment to ototoxicity, I realize that there was an irony in my blithe trust in the benignity of medical intervention, since in my case, it led to permanent impairment.

Because of what happened to me and thousands of others, I believe that gentamicin should not be prescribed without the patient being told of possible permanent damage, and being allowed to make a decision on the basis of knowledge: informed consent. I consented to treatment before surgery but I was not told that I would be given gentamicin, or that it might destroy my balance system. It seems cavalier to give a patient a possibly toxic drug so casually. Yet when my symptoms appeared the doctors who were looking after me instantly made the connection between my condition and the gentamicin I had been given. After my post-op check-up, when I asked my surgeon, "Can I

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keep in touch with you?” and he replied, “Yes, but only if it’s about the surgery”, I did not understand what he meant, but I think now that he wished to distance himself from the gentamicin damage, from any responsibility he might have for my condition.

I wasn’t angry at him then, and I’m not angry at him now. He thought he was doing his routine best for me under the circumstances. Yet his prescription of gentamicin to prevent possible post-operative infection was an instance of what Ivan Illich, in his book *Limits to Medicine: Medical Nemesis: The Expropriation of Health* calls “clinical iatrogenesis” (from the Greek *iatros* meaning physician, and *genesis*, meaning “origin”) (11). Gentamicin ototoxicity is an iatrogenetic disability, caused by medical intervention. One wobbler wrote that when he has to go into hospital for any reason at all he writes on his body with indelible marker, “Rather death than gentamicin”, except that in his case it’s too late: the damage has been done.

As a result of my surgeon’s well-intentioned but careless prescription, this is how I am constrained to live, staggering through what remains a wonderful world. I would not go so far as to rejoice over the loss of my balance system because of what it has taught me, but once it had happened, I looked on it as my fate, as what was waiting for me on my life’s road, something given to me to learn to live with. Since then I have been through three other major surgeries which left me thankfully pain-free, alive, and still a wobbler. I have learned to value what gentamicin damage has given me: a rare perspective on the world, on the dynamics of locomotion and vision, on the miracle of human adjustment to life on Earth. Something in me insists on looking at what I have

gained, rather than at what I have lost.

Can I hold these two attitudes at once? On the one hand, an overwhelming sense that a toxic drug that can hamper someone's life forever should not be allowed, on the other a sense that I could not have learned in any other way what I have learned from gentamicin toxicity? Since it is my long habit to think of analogies from literature, I think of the Ancient Mariner who felt constrained to tell his tale, a narrative of misfortune and a changed attitude toward the created world because of an error committed by him. In my case, I feel constrained to tell my cautionary tale, a narrative of a restricted and sometimes difficult life, together with a skewed perception of the world, because of an error committed not by me but by someone else. I say: it happened, it is irreversible and I have learned two only seemingly incompatible lessons: gentamicin should not be given to a patient without warning of possible irreversible damage, and gentamicin damage has led me to new understanding of my own inner resources, of the comfort of a community – in my instance, the wobblers—and of the marvel of our adjustment to living and moving on the Earth, an equilibrium developed over eons and dependent on an inner system of controls that seems protected – the inner ear – but that is penetrable by an intravenous drug.

One of the problems in telling a wobbler's tale is that it is almost impossible for listeners or readers to understand what it feels like to see and experience the world as we wobblers do, how weird it is to live in a world which seems to imitate what our bodies do, rather than existing independently of whether we move or are still. It is, at first, a kind of waking nightmare, as though we have lost control of

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our bodies and have gained a bizarre control over our surroundings. It goes against the grain of how we know things should be. The world should not imitate us. As we learn to control our movement through space under these new conditions, as we regain our confidence that the stair we are about to put our foot down on is not, as it appears to be, moving, but is, as it should be, stable, we gradually regain our confidence. But it remains a kind of intermittent oppression, a burden, to have to continuously discount what our eyes seem to be telling us, to have constantly to make mental adjustments about the difference between what we seem to see and what we know to be true. We have to learn to control our bodies in a world which seems drastically out of control. It gets better, but it never stops.

I don't feel able in this day and age to go up to persons as the Ancient Mariner did, button-hole them and cry "*There is a drug*" as he cried "*There was a ship,*" so I have written this record of what happened to me, how it feels to live as I and others damaged by gentamicin do, and what I have gained from this experience. Our adjustment to being alive on the Earth is a kind of natural miracle, and only an interruption in this exquisite exchange makes us aware of it. But the wobbling path to enlightenment through gentamicin damage is so extraordinary, so outside the norm, that it deserves its own tale.

I have told my version of it.

Just the other day I went out in a car with my daughter, held her hand as we walked to the pebbled beach, thought, "I'm managing well; I'm not really disabled". Then as I put my foot on the uneven stones I began to weave about, unable to stand or step. Still clinging to my daughter's hand,

I moved over to the exposed pilings of the pier and edged my way along them so that I could stagger to the water's edge and sit on a stone while she swam. Another reminder, another small triumph, another daily miracle: to sit very still on a stone in a world that now seemed stable, to watch someone I love splashing in waves, to feel so happy to be there that it did not occur to me to regret that I can no longer join her.

Works Cited

Laurie Anderson. "Walking and Falling" from her Album/ CD *Big Science*.

Joseph Campbell. *The Power of Myth*: Doubleday, 1988.

Arthur W. Frank. *The Wounded Storyteller: Body, Illness, and Ethics*: The University of Chicago Press, 1995.

Ivan Illich. *Limits to Medicine. Medical Nemesis: the Expropriation of Health*: Pelican Books, 1977.

"The Verse Record of my Peonies: A Diary of an Illness" in Earl Miner ed. & transl. *Japanese Poetic Diaries*. Berkley: University of California Press, 1969.

Christopher Nolan. *Under the Eye of the Clock*. New York: St. Martin's Press, 1987.

Christopher Nolan. *Dam-burst of Dreams*. Pan Books, 1981.

Gillian Rose. *Love's Work*. London: Chatto & Windus, 1995.

Oliver Sacks. *The Man Who Mistook His Wife for a Hat and Other Clinical Tales*. New York: Summit Books, 1970.

Abram Tertz, (Andrei Sinyavsky) *A Voice from the Chorus*, Translated by Kyril Fitzlyon and Max Hayward Yale University Press 1976.

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