

# And Still I Fight

by Kathleen Rockhill

*L'auteure qui a subi un accident d'auto grave nous parle de sa réadaptation physique tout en discutant des questions de privilèges et d'handicaps.*

*I think a lot about privilege, about how to rupture the taken-for-granted right to be that accompanies privilege, how to see through the limits of my class and race privilege.*

May, 1993

It is not so long ago that I was a relatively healthy able-bodied woman. A feminist committed to challenging the hegemony of privilege in defining human rights, I knew all the right words, even had the right sentiments. I cared about access; sometimes I included "differently abled" in the string of qualifiers I attached to the universal concept "woman."

I once had a lover who was less able-bodied than me. I learned to be sensitive to her limits, to her contradictory needs to be independent and cared for. Sometimes I raged with her at the unthinkingness of others. Sometimes I got frustrated with her for not even trying to do things I cared about, like hike or canoe. I took it for granted when she did what I could, never fully appreciating how hard she must have had to push herself to do what I did so easily. Really

I didn't have a clue  
All I knew  
was that I didn't want to offend, or leave out, or erase  
or be insensitive or unsupportive  
Most of all ... I wanted to  
*do the right thing*

I was not able to live with every breath of my body, to see in every photo my eye fell upon, to feel in every eye that nervously shifted its gaze from mine, to sense in every room I entered, to remember in every activity I undertook, to read in every line I read, the reality, the difference, the invisible concrete walled-off boundaries, between the "able-bodied" and those restricted by a society that doesn't give a shit about their presence; a society that doesn't feel the absence of those whose bodies don't conform to the physical demands/assumptions of normalcy.

Mentally, emotionally, I have been the disabled one,

limited by the prerogatives and fears of "the normal" from appreciating the complex worlds of the "differently abled"; ignorant of the riches and poverties that separate out, that denigrate and dismiss, vital lives that I was too ignorant to miss, so framed have I been by the stultifying world of "the normal," the ever-present ever-invasive images that draw me, images that haunt me.

It saddens me greatly to think of this: that I do not know, do not feel in my bones, the plight of those socially cast aside as "other," until I have lived it. Twice this has happened to me now. First, when I "chose" to identify as a lesbian, and then when I was hurled into the world of disability, not an identity I would choose, given the choice ... and yet ... and yet ...

*The arrogant ignorance that privilege nurtures*

What does this say? What hope does this hold out? Can we ever learn to see, to feel, beyond the walled-off boundaries that privilege builds? To know, to feel so intensely that we cannot forget, what it is like to be to be cast outside the easy assumptions of privilege, what it is like to be ignored in the wastelands of indifference, to be left in waiting upon the patrons of good intentions?

Like access ... so they put up the blue wheelchair sign ... maybe even put in a ramp, or a bar or two (if I can manage to get to the toilet and some able-bodied person hasn't perched herself upon it) ... designate a parking spot where they are sure no able-bodied people will be inconvenienced (if yet another able-bodied person has not chosen to ignore the signs) ... and that means access ... (I've yet to see an able-bodied person call the police to report that a designated disabled parking space is blocked. Have you?)

so conscientious, so good they are  
I want to **SCREAMMMMMMMMMMMMMMMMM**  
Carry a can of red spray paint with me wherever I go  
wage guerrilla warfare

I think a lot about privilege, about how to rupture the taken-for-granted right to be that accompanies privilege, how to see through the limits of my class and race privilege, how to work with others dedicated to the politically in/correct mantra, working to right the violences of the "isms" of gender, race, class, age, ability, sexuality, ethnicity ...

Maybe the most I can ever hope for is to know that I don't know; to listen, really listen, as if my life depended upon it.

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June 18, 1993

In memory of Lois Heitner

*Whoever I am*

*I must believe  
I am not  
and will never be  
the only  
one  
who suffers.*

—Cherríe Moraga

*Ready or not i must go out into this world alone,  
learn to overcome my limits, my fears, learn to accept  
what i cannot do while endlessly pushing myself to  
take yet another step, to look fear in the eye.*

How could she die? Another statistic. Another fatality on the 401. The agonizing nightmare. No words come to capture her light, her laughter, her intensity, her energy, her determination, her fight. No words to capture the loss to all who knew her, the pain her lover must suffer.

Her spirit haunts me all this week. Ever since that early morning moment when Jaki called:

I am getting ready to make my first drive alone, getting ready to go to Peterborough to begin the terrifying business of replacing the vehicle I crashed; getting ready to do what I am not ready to do, what I am terrified to do, what I must do if I am to continue to live in the country

getting ready to do what I am not ready to do  
fear so great the only greater fear I know is to let this fear win  
getting ready when the phone rings

Jaki? What's wrong?

**NO!NO!NO!NO!NO!NO!NO!NO!NO!NO!  
NOOOOOOOOOOOOOOOO!!!!!!!!!!!!**

LOIS? Lois, oh Lois oh lois how can it be i cannot let it in all night it tears at me i put you away day after day no one wants to know no one wants to hear no one can let themselves know the agony no one can go near their greatest fear there is no room for tears the tears that tear at my heart the tears that no one wants to see to know to feel the tears that creep into my restless sleep the tears that speak what no one wants to hear

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Except Becky. Does she know? Some of the time I feel like maybe she does. We have lived through it together all these months death so near it nearly chokes us

and now it's time  
ready or not  
my time is up  
Becky has to move on, to live her life  
no longer can she be my cushion  
hard reality glares

ready or not i must go out into this world alone, learn to overcome my limits, my fears, learn to accept what i cannot do while endlessly pushing myself to take yet another step, to look fear in the eye, to know that I too will die and there is no way i can control where when or how

*let me never forget the pain I have suffered; let me never forget that in the hours of my most excruciating agony, I would have given my life to be where I am now*

When I despair I take out the photos Becky took the day after the accident.

It takes my breath away to see my smashed up truck to see the cold collapsed metal to see the damage to the driver's side, to imagine how I survived; to see the damage to the passenger side, so thankful that I was alone.

It takes my breath away to see the smashed-up carcass  
**NO**

**IT IS ME**

It is my smashed up body lying there, legs pulled apart, pinned down by the weights of traction. Eyes swollen shut against the pain, bruised puffed-out cheeks, nose in stitches, mouth set in a grimace, blue hospital gown against stark white sheets. White purple red skin stretched over the broken frame of bones conceals the damaged nerves that die within ...

**ALIEN**

Except for that wrist wrapped in hospital bracelets of plastic. Every time I see it tears come to my eyes. So vulnerable. It is set there like a broken bird's wing just above the huge purplish hand that lies listlessly upon the clean cotton sheets.

They tell me I have to look ahead, think positive, not give up hope, not look back, have faith that I will walk again, that everything will be all right. Maybe. I don't think so. "You don't think so now, but everything will be OK. It will be. You can't give up hope. You have to think positively. You'll be just fine. You'll see."

**NOT ME**

Always when I get scared, when I feel the dull pull of despair, I have to go back to that place of my greatest pain, to remember what life demands I forget. To remember back to that time when I would have given anything to be where I am now, to know again that I want to live, that I

can take pleasure in little things, like being able to see the flowers bloom, hear the bird's song, feel the warmth of the sun against my skin, breathe deep the misty clean air brought by the spring rain.

*Sometimes it works. My life in clichés.*

*A constant balancing act, walking the tightrope between remembering and forgetting*

Just to balance, to walk again—to feel the wet grass beneath the soles of my feet, to feel my weight centred low in my limbs, that delicate ecstasy of power charging through the earth, travelling up through my soles, through

*How do you measure homophobia? Is it in the way I am treated—with complete disrespect? In the way they treat Becky, who they ignore day after day as she comes to give me the care they will not give?*

my calves, through my thighs into my pelvis, gently rocking me to the tune of life's sensuous call  
**GONE FROM ME.**

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*July, 1993*

How to buy safety? How much does it cost?

I have the privilege of having a choice. Can I buy enough metal to put between me and all that might harm me? Can I buy enough metal to ward off rapists, homophobes, burglars, killers? Can I buy enough metal to overcome my fear? Can I buy enough metal to compensate for my paralysis?

And if I had a gun, would I have enough metal to shoot? How much does it cost to buy safety?

How much metal do I need to surround me, to protect me  
driving the 401  
limping along the streets of Toronto  
living, partially paralysed, alone in the bush of the north country.

I buy exactly the same vehicle as I crashed.

Did its reinforced steel sides and roof save my life? Or did its height tip me to my near death? I torment myself. Finally I choose life. Pat says it takes a lot of courage to buy the same vehicle. Still it takes my breath away. Am I being just plain stupid? Is there any way to predict, to know, to buy, safety?

How much I have to make myself forget. To get behind the wheel again. To stay alone in the north country. To drive the icy winter roads. To face down my fears.

Each moment I am behind the wheel, I relive the accident; every time I come upon a sharp turn my breath drops through the floor waiting frozen in fear to see if

anything's coming at me around the bend. I feel so small so broken now behind the engine's power. What's a middle-aged crippled lady like me doing with such a macho vehicle?

My wheels. My dykemobile. My Black Beauty. My strength. My power.

Each day I hoist my body up onto her lap, get behind her wheel and come a little closer to feeling at ease with her again.

One day I will ride with her again, glide with her over the rolling hills, smoothly turned curves opening out onto the long narrow expanses of breathtaking country roads.

I will.

This is new for me, this fear. Always, before, I made myself face fear down. I would hurl myself headlong into the abyss of my fears, yell out to the demons to come get me if this was my time, dare them until they went away. No way they were going to rule my life.

My spirit is broken now.

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*August, 1993*

I read back through my journals since the accident. The unrelenting pain a memory now.

I flip flop. One day thankful to be alive, the next anguished by my limitations, my losses.

The hospital in Peterborough. Searing pain. Nurses scold me for taking too many pain pills, scoff at my "complaints" of being unable to breathe, of pain caused by the rod rammed into my pelvis. Spasms through my leg jolt my entire body like bolt upon bolt of lightning. Sleep never comes. There is no escape. Pinned down. Alone. In my raging frustration, I fear I'll hurt myself. On the 7th sleepless night I hire someone to sit with me; she comes for three nights, when, at last, I succumb, for an hour or two, to sleep.

The hospital ordeal lasts for 6 weeks and 1 day. A long lonely stay. I am at the mercy of nurses who treat me like a piece of rotten meat. Except for Dorothy, who saves my life one night when she convinces the specialist to check out why my breathing is so laboured ("You almost died twice," she tells me as I'm leaving). Cindy and Linda manually unpack the block of constipated shit that my bowel will not release. A fourth nurse whose name I do not know, sits quietly at my bed for several minutes at a time during the agonizing nights when sleep never comes. I wonder if she is a dyke.

How do you measure homophobia? Is it in the way I am treated—with complete disrespect? In the way they treat Becky, who they ignore day after day as she comes to give me the care they will not give? When she asserts

her concern as my partner, she is subjected to seething scorn by the respiratory specialist who threatens not to perform the dangerous procedure he has said is necessary to my life; Bec has had the "audacity" to ask him about his success rate with the operation. He is the only choice I have. Furiously, I lick ass; as much and as fast as I can, anything to mollify him to feel safe enough to have him perform the goddamn "procedure." Then there are the nurses who lift my arm and ask one another: "Have you ever seen hair like this under a woman's armpit before?" Day in and day out indignities as they refuse to give me my pain medication, ignore my pain, throw my leg around as though it's a sack of dirty laundry, belittle my needs, laugh at the amount of pills I'm taking. How do you measure homophobia?

Turns out I had pneumonia. Turns out there was a build-up of fluid in my lungs caused by a fractured rib that had punctured the lung's lining. Turns out my pelvis was fractured. Turns out the metal bar of the splint they used for traction was rammed right into my cracked pelvis. Turns out my fractured femur was "highly unstable." Turns out there was irreparable damage to my sciatic nerve.

Gradually it dawns on me that I will never "get better," that I will be crippled for life. I finally utter those words to Bec, asking how she can live with a cripple, sobbing that it is more than she has bargained for. Bec rocks me in her arms, crying, "don't say that, don't call yourself a cripple." But I am crippled. It's the only word that feels real, the only word that captures the pain I feel, the only word that captures what I must live with, forever.

As I get ready to leave the hospital, terror sets in. I cannot bear to be so dependent on Becky. I've found her mood swings while I am in the hospital frightening. She's scared about my coming home, about all the responsibility it puts on her. I'm terrified beyond all reason of how dependent I am, how trapped I am, unable to care for myself, unable to protect myself. Barely able to move, I am a total burden.

Watching. Weighing. Waiting. In the weeks that follow I struggle with my limits. Ever mindful of Becky's moods, fearful of igniting her anger, I am constantly looking for the right moment to ask, to dare to risk, throwing me back to the terror of my childhood:

*what can i ask for? what can i push myself to do? how can i think creatively about meeting my needs? what can i do without?*

No matter how I try to spare her, constant work is required of Becky, as she must not only care for me but assume responsibility for all the household chores I once did. The two of us alone up here, Bec is my sole source of contact with the outer world—shopping, doctors, therapists—all my needs fall on her shoulders. She is too exhausted for pleasure. Pleasure becomes synonymous with not having to be responsible for me, or so it seems to me.

Friends urge us to move back to Toronto where we can have more support. We cannot bear to give up our home,

our woods, our river. Where would I stay in Toronto? I can't walk, can't handle stairs. How would we move? Who would do the work? Bec insists she wants to stay.

I feel the heartbeat go out of my home, out of my life. There is no music. There is no movement. There is no warmth. I am confined to the house. I sit two feet away from the stereo I can no longer work. I watch the cold black wood stove that I once used to heat our home go unkindled. I become aware of how I used to be in a state of perpetual motion, especially in the evenings as I rhythmically glided from chopping vegetables, to stoking the fire, to changing the record, moving to the beat of my favourite music, *The Indestructible Beat of Soweto*, volumes 1, 2, 3 and 4, grafted onto my body. Now, it breaks my heart to hear it.

Bec and I are in deep trouble; we are drowning under the weight of my need, our private pains. I am scared by Becky's need to find her pleasure away from me, time when she can feel free of responsibility for me. We bring to our troubled situation, troubled histories, violent pasts that poise us, like the clashing clang of cymbals, in opposition as we dance the tangled dance of taking care of/refusing to erase oneself/in the face of the need of the other. We both want, desperately, to be *seen* by the other.

My mother and grandmother schooled me well to never, under any circumstances, be a burden. Like them, I cannot imagine that someone might love me just for who I am. The accident has wiped out any sense of power/value I had: my capacity to care for others, my generosity, my sensuality, my sexuality, even my mind. I cannot imagine why Bec would want to be with me. I feel her unhappiness. I am terrified that she will leave, a terror intensified lightyears by the knowledge that I cannot live on my own.

I am acutely aware of how my sense of power has been defined sexually. I revelled in feeling the earth's energy rise through the soles of my feet into my pelvis. For many years I had worked to overcome the physical/sexual effects of incest in my body by teaching myself to lower my weight deep into my pelvis, to move with my "cunt open," to feel the power of my legs. When I am first able to stand after the accident, to begin to bear weight on my paralyzed leg, I howl at all I have lost. I am unable to feel anything through the hollowness of my leg, the plastic brace that holds my foot in place.

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*January 30th, 1994*

Eighteen thousand kilometres on my vehicle since July, travelling from one therapy to another: acupuncture, chiropractor, trager, massage, psychotherapy. Daily exercise routine of two plus hours, one hour a day on the acupuncture machine, nightly hook-up to the muscle stimulator machine.

getting stronger, oh so slow. leg shows no signs of regeneration ... hobbling around the house like a jack rabbit with a pegged leg.

The bloody exercise bike comes to symbolize how I feel:  
Cycling my brains out

no matter

how hard i work how fast i cycle how much i push myself  
I am eternally **stuck** in one place

Silence so deep

*strangulating isolation*

**SCREAMING** my heart out when I cannot bear the  
silence another moment

**GOING NOWHERE**

Day in, day out I fight to keep going, not to give up hope  
in the face of despair

*endless*

*monotonous*

*battle*

*courage*

*anguish*

*fear*

I have travelled more in these many months than I have in  
my lifetime

**GOING SOMEWHERE**

I never imagined

Bec and I have made it through

so far

Wounds sealed deep beneath details of the every day

I don't know how I'll get by, how I can continue to live  
in the country, how I'll manage to work, if I'll be able to  
walk or feel the grass under the soles of my feet again.

Layer upon layer of hope gives way to the agony of  
acceptance

*And still I fight.*

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*November 6, 1995*

I resist the urge to wrap it all up; to tell you what has  
become of me now, 21 months after my last entry, 3 years  
to the day since my accident; to create a linear narrative  
with a beginning middle end. I resist the urge to comple-  
tion, clear only that, however much I may think I know  
where or who I am, and project that stasis onto the future,  
I never know what's coming round the bend.

Instead I want to pick up the thread with which I  
opened this narrative. The question of privilege. Interest-  
ing that this was my starting place, the subject of my first  
piece of reflective writing on the accident. Odd, really  
odd, as I look back that that is where I would begin. An  
academic question. A political question. And yet, it is one  
that continues to interest and unsettle me.

Compared to other disabled women, I am "privileged,"  
both materially and physically. While I am seriously  
limited in my ability to walk, I am not confined to a  
wheelchair or a scooter; in order to buy a house in  
downtown Toronto that could accommodate my physical  
limits, I had to assume a huge mortgage, a mortgage I  
worry about being able to continue to pay when the auto  
insurance portion of my income benefits are cut off today.  
But I was able to qualify for the mortgage; I have a lovely

home for as long as I can manage the payments, for as long  
as I can manage it physically.

What is privilege? What does it feel like in the texture  
of everyday life? Money counts. A fully functioning body  
counts. A presence that is desired by the dominant society  
counts. The power to define "reality," for one's self and  
others, counts. Still, the dichotomized hierarchy of either/  
or, of privileged or not privileged, obscures the contradic-  
tory and complex ways in which power works to define  
im/possibility.

One way in which I understand the terror I have lived  
since my accident is as a story about my "fall from  
privilege." This is an overdramatization, but it does cap-  
ture how I've felt my life taken from me. The foundational  
assumptions upon which my subjectivity was formed were  
framed through an unarticulated sense of my location in  
relation to privilege. In some ways I continue to reap the  
rewards of my accumulated privilege; it is the heritage of  
that privilege that helps me in my fight. I am highly  
educated, articulate, know how systems work, do not  
settle for bureaucratic limits, know how to pursue my  
rights from decades of having assumed and/or fought for  
them. When I no longer enjoy the rights I once did, I am  
outraged. I fight. What has changed is that I rarely win.

When I reflect upon my account, when I feel the fear  
that envelopes me, when I let despair have its day, it is my  
"fall from privilege" that I feel so acutely. Physical limits,  
my inability to accomplish that singular goal of the  
insurance companies and their endless line of rehab spe-  
cialists—the goal of full-time work—my refusal to sacri-  
fice the body I have left to that all-important goal, leaves  
me at the mercy of bureaucrats. They do not respect me as  
a fighter, they do not care about my well-being; their job  
is to cut my benefits. I am defined as uncooperative when  
I resist their plan for me. I worry financially in a way I have  
not before; there are no other jobs where I can meet the  
underlying assumption/demand of physical normalcy. I  
am dependent upon my employers as never before. Who  
else would hire me? Who wants to accommodate a partial  
cripple who cannot perform as though not crippled, like  
the publicly packaged Lucien Bouchard? So I do what  
Mike Harris says all disabled people should do, work at my  
old job for half the pay so that I can meet the assumptions  
of able-bodied standards.

My life is at the mercy of the medical system. Not  
physically. There is little that they can do for me. They  
hold the power of assessment, of defining whether and  
how much I can work, what benefits I'm eligible for, what  
therapies I undergo. I now see my choice of doctors as  
about politics. To get support for non-western therapies,  
like acupuncture, I must have an approved western-  
trained doctor testify to its necessity for my healing. To  
refuse to see the specialists my insurance company sends  
me to, or to refuse to engage in the programs they endorse,  
is to jeopardize my benefits. My body has been taken over  
by an endless barrage of medical practitioners, each of  
whom works on a different piece of me. I long for an

advocate, someone on my side, fighting for and with me. Not only am I positioned as a "client" in this system, and an "uncooperative" one at that, but also as one who doesn't want to work, one who will do whatever she can to milk the system.

The subtext, of course, to my being positioned as "uncooperative," is that I neither look like, nor behave, as a "nice white, middle-class, middle-aged lady"; I refuse/no longer *can* perform myself heterosexually, or camouflage that I'm a dyke.

I become sullen and angry. I do not want to deal with yet another professional where I am asked to repeat the details of my accident and its effects; I am sick and tired of justifying myself, of telling yet another deceptively kind face that "I love my work. I want to work; that's not the problem." It's my body and its inability to conform to the assumptions of your world that's the problem, not my "lack of motivation."

*I refuse to be your victim.*

Another way in which I feel my "fall from privilege" is in my coinage as a sensual, sexually attractive woman. I am struck by how I learned to perform my body so as to maximize my sexual capital. It's about my pleasure and desire, and it's about how you see me, how your gaze positions me. I work hard to counter the physical "deformities" of my body, to look "normal." My gait is getting better, my centre of gravity is gradually shifting from my shoulders downward, but walking with a limp and a cane, a leg that flails out to the left, is not the way I would choose to perform myself, given the choice.

I have "special needs" now—needs that don't go away. I've come a long way from those early months; still I am seriously limited in what I can do. In the breakup of my relationship, one of my most painful moments was when Becky told me that she had not been able to ask herself whether she stayed with me out of love or out of her inability to abandon me in my need. I am thankful that she stayed during my hardest time; I do not know how I could have gotten by without all that she did for me—and it's a soul destroying way to be loved. It's true, there was little space for her pain, for how her life was radically interrupted and turned upside down, *and* she was free to walk; eventually she did. Becky and I are not alone in this struggle with the "burden" of another's needs. Power in relationships radically inverted in that "fall from privilege."

To be sure, I'm still privileged. While I'd give anything to have my legs/my body back, it sure is easier being paralysed with financial resources than without.

*I don't want your pity.*

I am troubled by this concept of privilege. I want to stop attaching privilege to individuals, as though it's a state of being or a commodity that one does or does not have, and to think instead of acts, of what it is that one can do, in varying situations, and in relation to whom. Privilege is about power, the power to effect the actions of others, the power to exert some control over one's life,

to know the possibility of choice and rights that are inscribed by "the normal." Power is about having value, that is, skills, abilities, performances, that effect possibility for others, that others desire. We learn to perform ourselves in ways that will maximize our power to realize our desires. That these desires are socially constituted matters. Who desires to be disabled? Who desires to be around "disabled" people? We are socially organized out of society. Our absence is not missed. Because the disabled are pitied, defined as tragic, a burden to society, our insights and capacities are not prized—they are not even recognized. Since my accident I may be a "better person," even a "better worker," but what I have to offer is not what counts in a society possessed by the production of "the normal," the material idealization of bodies and achievements.

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*March, 1996*

I see little choice  
now  
I fight for my life  
up against  
webs of callous indifference  
webs spun of  
the arrogant ignorance  
that privilege nurtures.  
Exhausted  
this tired body  
breaks down.

*Tired of fighting ...*

I think a lot about the politics of "disability." What does it mean when those of us with vulnerable physical resources, most with severely restricted economic resources, are left to fight "our own" battles? Or when we are left in waiting upon the patrons of good intentions, who do not exactly see the plight of "disabled dykes," or queers, as their rallying call? What will it take for lesbians, gay men, queers of all colours and classes, to see that our politic cannot be limited to our sexuality? To see that our bodies, our desires, our differing "needs" and the various discriminations we must face day in and day out, are intensified by, at the same time as they transcend, our sexual preferences and practices?

*A version of this article will appear in Pushing the Limits: Disabled Dykes Produce Culture (edited by Shelley Tremain, Women's Press, 1996).*

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