

sinister wisdom 39



ON DISABILITY



Sinister Wisdom 39 Winter 1989-90

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Pat Parker lived from January 20, 1944
until she died from cancer on June 17, 1989.
This issue of *Sinister Wisdom* is dedicated to her:
to the spirit she shared with us,
to her spirit that goes on,
informing our work and our love.

Love Isn't

I wish I could be
the lover you want
come joyful
bear brightness
like summer sun

Instead
I come cloudy
bring pregnant women
with no money
bring angry comrades
with no shelter

I wish I could take you
run over beaches
lay you in sand
and make love to you

Instead
I come rage
bring city streets
with wine and blood
bring cops and guns
with dead bodies and prison

I wish I could take you
travel to new lives
kiss niños on tourist buses
sip tequila at sunrise

Instead
I come sad
bring lesbians
without lovers
bring sick folk
without doctors
bring children
without families

I wish I could be
your warmth
your blanket

All I can give
is my love.

I care for you
I care for our world
if I stop
caring about one
it would be only
a matter of time
before I stop
loving
the other.

A Journal for the Lesbian Imagination in the Arts and Politics

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When I brought the first draft of these editor's notes to my writer's group, they said I wrote as if I were out of my body. They said: here's an issue on disability — you've set an expectation of personal writing for the notes, and you're not located within what you've written. Write about your own disability, they said, or at least write about why you're not writing about it.

The topic of disability seems enormous to me tonight. I want to say the work of the womyn in this issue is enough. Read what they have to say. Their words are direct, important, immediate. They address a wide range of disability issues, probing the personal and political, sharing intimate experiences and challenging community complacency. While the contributors' viewpoints are varied, we don't intend (and couldn't possibly make) a comprehensive anthology on disability and disabling disease. This is one issue of one lesbian magazine. What's critical is that these topics become commonplace: matters for daily discussion, basic parts of our consciousness when we do things — plan parties, go to the movies, organize demonstrations. In putting the issue together, I have felt like its functionary, its technician: trying to carefully implement the opinions of the editorial group*, working with the writers and other editors to get the clearest, most balanced issue possible from the work we received.

And the topic still seems enormous. I'm a little burned out from doing *Sinister Wisdom*, my life, my typesetting job. I want to think I have endless stamina, reserves of endurance and patient resolve I haven't begun to tap. The truth is I am somewhere beyond my capability and I don't want to admit it. I have different forms of chronic pain from different sources; I am willful and the pain "isn't so bad, mostly." It's difficult to write about stages of denial when you're in the middle of them, even if you know you are. It galls not be able to do what you know you can do because

*Over half of the regular group of editorial readers are disabled; several disabled lesbians joined specifically for this issue. Many of the dykes involved with *Sinister Wisdom* did a tremendous amount of editing, suggesting and background work for this issue. In particular I want to acknowledge the contributions of Caryatis Cardea, Jasmine Marah, Naja Sorella, SusanJill Kahn and Barbara Ruth.

you have reached your physical limit, because pain interrupts you. There's a difference between working up a sweat (even a sweat of the mind) and wearing yourself out. Of course I want to believe/act as if I can't wear out. Not yet, not when the real work, when the fun of the real work is just beginning.

It's hard not to compare, to say the ways that I'm disabled are small next to others, to the womyn whose work is included here. I have no clear definition of what disability is for myself. No matter how difficult or painful my life, there are innumerable women whose lives are harder. The point in making lesbian space is to encourage each of us to tell our stories without self-deprecation. It's not about playing queen for a day. Our impulse to compare and to rank often creates more distance between us, keeps us from paying attention to what's really going on inside us. When we aren't paying attention to ourselves, we often end up resenting other womyn's demands. It's too easy to fear that there isn't enough room, enough space, enough time. That the ones who need it most won't get heard. That maybe the ones in need who won't be attended to will be us. Or that we'll take the space away from someone who really needs it with some minor complaint, and be consumed by guilt for the rest of our lives.

So many factors influence how we experience our disabilities. Money. Degrees of mobility. Family relationships. Community structures. Cultural/ethnic/racial backgrounds. Whether our disabilities are progressive or stable; whether they're visible or hidden; whether they're life-threatening; whether they're clearly diagnosed or mysteries to Western medicine; whether they cause us pain; whether they break up regular sleeping and eating patterns; whether we grew up with them or they were caused by disease or accident later in life.

Many dykes want to be independent and self-reliant at any cost; as women*, many of us were brought up to be dependent and subservient. Disability can increase that emotional friction unendurably. Whenever we come in contact with an institution around our disabilities, those institutions demand our imme-

* I use "womyn" and "womon" for dykes or primarily dyke groups. I use "women" for the constructed class of females in patriarchal contexts, "woman" when I know the woman about whom I'm writing is straight.

diate submission to their paternalism; often even our well-meaning lesbian health-care practitioners want us to follow their systems to the letter — if we don't, well, we bring the consequences on ourselves, don't we?

I stop and think about how many times I've watched the medical system steamroll over some woman — in emergency rooms, new-age doctors' offices, establishment pain clinics, alternative healing centers. Cultural dominance and submission get played out everywhere, on every level. A certain hat-in-hand attitude is expected of "lay people," of women, of disabled women even more. Often the result of being subjected to constant paternalistic crap is for women to fetishize certain things that appear to be within our control. That is, we fix our attention on some small, useful activity that we can do (never eating wheat, meditating to relieve stress), to the degree that we are distracted from seeing political and social patterns. We get so many double, triple, contradictory messages about how to take care of ourselves, how, if we're still sick, in pain, uncured, we must be doing something wrong, it must be our fault. Then we blame ourselves for succumbing to self-hatred, and the process which keeps us going in circles is complete.

Sometimes, no matter what we know, our internal voices insist there really *isn't* enough room or resources for everyone to get their needs met and we must be doing something wrong anyway if we have such pressing needs, but if we're good and don't complain, the nice doctor will make us all better, you'll see.

Disabilities take place within contexts. Those contexts are usually designed to minimize the presence and the "inconvenience" of disabled folks. In the lesbian community we have, in fact, done a tremendous amount of work on access consciousness — many of us agree that community spaces should be ramped, events should be signed, special seating should be provided for vision-, hearing-impaired and fat womyn, large print programs and materials should be available, journals and books should be taped, and scents, perfumes and smoking not allowed. But we seem to be carrying out these agreements less, not more, over time. Is it that we're so self-absorbed we "forget" who isn't with us? That we've made priorities that exclude each other? That we

still hold values about who is and isn't worthwhile, productive, valuable? Every dyke deserves the option of inclusion in our events, our struggles, our celebrations. All of us can insist on inclusion and access, can move our consciousness into action.

As our actions change our lives, our words change our actions. By far the most common negative metaphors I come across in lesbian writing are ablist: "it cost me an arm and a leg," "blind to the truth," "deaf as a post" "lame excuse.* "

It occurs to me that the invisibility of disabled people is one of the reasons these metaphors are so prevalent. There's been a lot of discussion in the disabled lesbian and womyn's presses** in the last year on the use of ablist language, how much pain it can cause, how and when we should educate each other. The more we are insulated and isolated, the easier it is to use disparaging, trivializing metaphors. And the more we use those metaphors, the more our language becomes another barrier to access.

We need to pay attention to every word. The words we use and the words disabled womyn are using to command our attention. Start here.

* Certainly disability isn't the only area where negative qualities are attributed to states of being. Our language is full of images that equate light with good and dark with bad, or perpetuate stereotypes about ethnic and racial groups; language which characterizes old as weak, sexless, ineffective; careless use of words like "crazy"; language which links being fat with being slow, slovenly, ugly; which equates working class or poor with unmotivated, dirty, stupid. We encourage writers to accept responsibility for the on-going creation of language, and to apply lesbian imagination to every metaphor.

** See the resource list at the end of this issue for addresses of the disabled womyn's press. I am particularly referring to articles that have appeared in current issues of *Womyn's Braille Press Newsletter*, and *Dykes, Disability & Stuff*.

#40. On Friendship. Wonderful new work on what our friendships mean. Available in April 1990.

#41. The Italian-American Issue: *Sinister Wisdom* is currently soliciting manuscripts and artwork from all women of Italian descent, with a strong emphasis on work by Italian-American lesbians. Issue #41 will be guest-edited by Janet Capone and Denise Leto. Some themes will include *La Famiglia*: What does family mean to us? With each generation, how is our culture being maintained or diluted? *Lesbiche Italo-americane*: What does it mean to be an Italian-American lesbian? What factors have contributed to a delayed understanding of our ethnic and cultural identity? *Etnicità*: Do we see ourselves as Italian, American, or Italian-American? What does it mean to be olive-skinned? *La Storia*: What are the historical and economic differences between Northern and Southern Italy? How were the wave of immigrants from the South and Sicily pressured to assimilate once in America? *Stereotipie Culturali*: How has the image of the Italian as criminal or Mafioso influenced actual historical events such as the execution of Sacco and Vanzetti in 1927 and the mass lynching of Italians in New Orleans in 1891? *La Spiritualità*: What is our spirituality? Was it Catholic? What is it now?

Deadline: February 15, 1990. Send submissions or requests for further information and guidelines with SASE to Janet Capone & Denise Leto, Italian-American issue c/o *Sinister Wisdom*.

#42. Open. We have lots of ideas for themes and hot topics — and invite your suggestions for issues you want to see explored. But once a year or so we need an open issue for all the great dyke writing and art that doesn't quite fit the themes. Deadline: June 15, 1990.

Remember to check out the submission guidelines on the inside back cover before sending us your work. Thanks!

Contest

It was great, how many dykes took the time to write or type out the full lyrics of Willie Tyson's song "Did You Say Love?" which appeared on her album *Willie Tyson Debutante* (Urana records) in 1977. I wish we had room (and permission) to reprint the lyrics — you'll have to dig the LP out of your collection or borrow it from a friend, and listen again (if you missed Willie the first time around, she put out 3 albums, *Willie Tyson, Full Count* and *Debutante* — check 'em out). Many dykes wanted to know what happened to Willie ("has to be the women's music artist I miss the most"), and wanted her to know that they appreciated her work. Are you out there, Willola?

Winners of a one year subscription to SW (it was a tie): Mev Miller and Astrid Elsona Bergie.

And thanks to: Sandy Covahey, Evi Beck, Susanna Sturgis, Peggy Munson, Judy Freespirit, Marilyn Shatzin, Linda Giddings, Jane Meyerding, Nancy Hammond, Selma Miriam, Tara Ayres, Tina Gomell, Barb Gerber, Nancy Osborne, JEB, Liz Quinn. (If your name isn't on this list, we got your response after going to press.)

Subscriptions

Over 1/3 of our subscription list expires with this issue! If your label has the number 39 in the upper right corner, that means you. Now more than ever we need you to resubscribe — and while you're at it, send *Sinister Wisdom* to a friend (or two). Remember: resubscribe early — and often!

Apology

The drawing of "Calyakh Veyra, the Hag of Beur," by Max Hammond Dashú, which appeared on page 87 of #37, was inadvertently reprinted without a screen. Much of the detail, shading and depth of the original was lost by this omission. We apologize to both Max and our readers.

Barbara Ruth

Pelvic Mass Etiology

*for all the people who say or think,
"Barbara, why are you doing this? Again?"*

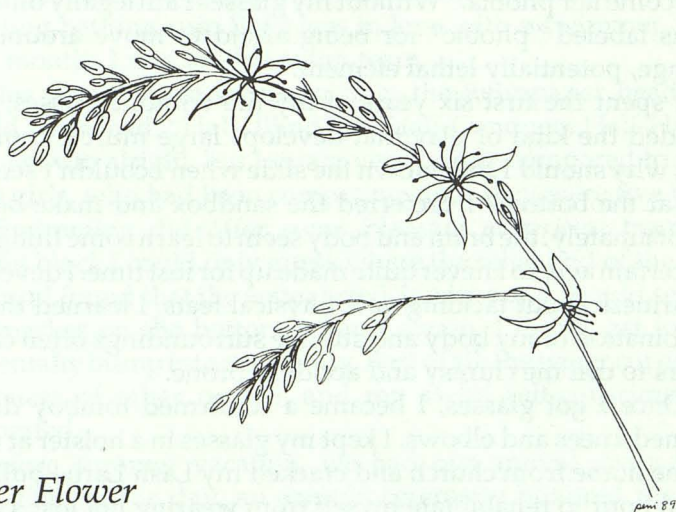
I think it all started with moving to Oakland
The fact I took birth control pills for fourteen years
My neurotic desire for a child
It's proof of bad karma in the second chakra
It's related to Halley's comet
Due to the fact I started menstruating early
It's caused by the patriarchy
By racism
Anti-semitism
Being on welfare
Or maybe it's sunspot activity
It's something I made because I want to be mutilated
It's punishment for enjoying sex too much
The wrong kind of sex
The wrong kind of partner
It's because I eat the wrong foods
It's choosing the wrong acupuncturist
The wrong Chinese herbs
The wrong visualization technique
It's too much vitamin C
It's my father trying to make me his son
It's this hard rock of anger
It's blaming myself
It's forgiveness refused
It's being an anarchist under advanced capitalism
It's my tax dollars
Invading Nicaragua
Investing in apartheid
It's not being a tax resister
It's going to jail in South Carolina to protest nukes
More Cesium in their water
Than anywhere else in the world

And that's what I lived on
It's being kicked in the belly by cops in Philadelphia
And then refusing to let the male ER doctor
Examine my bleeding ass
It's too much resistance
Or not enough
It's my great aunt kicked in the head
By cossacks' horses
It's my father's family bombed on reservation Redeye
Then sedated by condominium whiskey
It's the persecution of the Peyote church
It's too many psychedelics when I was a hippie
It's something I do
In order to get post-surgical morphine
It's something I do for attention
I do it in order to help
The surgeons work out their karma
I do it to meet the x-ray technicians
I do it in order to write this poem
It's punishment for being bad
For doing something so bad I forget what it is
But it probably happened before I was five
Or maybe before I was born
It's afflicted planets in my natal chart
It's genetic propensity
An unlucky roll of the chromosomes
It's having no homeland
Having my homeland taken away
It's forced relocation
It's Big Mountain
It's the Golan Heights
It's Thanksgiving and Christmas
Coming too close together
It's the long nights of winter
It's being battered by people I loved
As a child
As a wife
As a dyke
It's the toxins I breathe

It's the polar caps melting
It's the Coriolis effect.

I think it's the problem of entropy
The body's, the world's
Rushing toward ever increasing chaos
And I'm afraid there's not enough love medicine
In the whole universe
To make it stop hurting
To make me ever be well.

Reprinted from *Past, Present & Future Passions* — Poems by Barbara Ruth,
1986, W.A.T.R.



Spider Flower
Peni Hall

Amy Edgington

A Medal For Not Drowning

When I was eleven years old I fell in love with a girl I met on a camping trip. Kris was witty, sarcastic and smart. She took herself seriously as an artist, and she had the moral values I considered most essential in my friends at that time: she abhorred what we called "segregation" in 1957. Her German immigrant family was not as dully all-American as my own, and her Wisconsin accent sounded exotic to my Southern ears. My instincts told me Kris would not be open to sexual approach, but that did not stop me from wanting with every cell of my body to be as close to her as possible as often as possible.

This posed some difficulties: we did not go to the same school, and our parents didn't drive. We lived impossibly far apart when it came to figuring out the bus routes and schedules to get from my house to hers. However, she swam on a swim team at the YWCA downtown, and we could both take the bus there. One problem remained: I was terrified of the water. More than one adult had given up on teaching me to swim, saying, "She'll never overcome her phobia." Without my glasses I am legally blind, yet I was labeled "phobic" for being afraid to move around in a strange, potentially lethal element.

I spent the first six years of my life without glasses, and I avoided the kind of play that develops large muscle coordination; why should I slide down the slide when I couldn't see what was at the bottom? I preferred the sandbox and make-believe. Unfortunately, the brain and body seem to learn some things best at a certain age, so I never quite made up for lost time. I developed a wariness about tackling new physical feats. I learned that the combination of my body and strange surroundings often caused others to call me clumsy and accident-prone.

Once I got glasses, I became a confirmed tomboy despite skinned knees and elbows. I kept my glasses in a holster at night. I came home from church and cracked my Lash Larue bullwhip for an hour to rehabilitate myself from wearing not just a dress, but the added indignities of a purse, a hat and gloves. I played

tackle football in the street with the boys, until I was banned for breaking the quarterback's collarbone. Evidently I was even prone to other people's accidents.

At the age of nine I had had my first sexual relationship, but my girlfriend's mother put a traumatic end to our affair. By the time I met Kris, I was determined to hide all evidence of my sexuality, although that did not get rid of my feelings. I had also become embarrassed about my body. I knew I not only had "bad" eyes, I had a "bad" back. I have Scheuermann's disease. For reasons unknown my spine slowly twists into a more and more pronounced S-shaped curve, when viewed from the side and from the back. It's actually a spiral: I have seen trees shaped like me that look strong and graceful. Yet this is considered an ugly defect in humans, and in a female ugliness is the worst sin.

My ordinary adolescent paranoia about my appearance seemed to be confirmed by others. I had been muttered over by a series of doctors and physical therapists. I had overheard remarks about "the hunchback." In the first grade the other girls insisted that I play "witch"; they left me tied to a tree after recess was over, burning with humiliation. I did not feel ugly, but I suspected that others found me ugly. I knew that to go swimming once, you had to get completely naked in a room full of other girls twice; the rest of the time you had to run around in a terribly revealing bathing suit. But I was in love with a swimmer, so in three months I was on that swim team.

This was at least semi-amazing: the newspaper headlines should have read: "Half-Blind Girl Half-Conquers Half-Handicap." I swam alright, but I swam very poorly compared to most of the girls, who had been competing since they were five years old. Swimming did offer some pleasant surprises: from the starting block I could only guess where the other end of the pool was, but I found that the water acted as a lens and I could see the lane marker on the bottom when I swam. I didn't get lost or accidentally bump into somebody. Best of all, the water cut off my awareness of other people, and my awful self-consciousness evaporated.

Before summer vacation, we had our annual swim team party. During the day, an awards ceremony honored the outstanding swimmers for the most points accumulated in meets,

pool records in each event, and so on. Needless to say, I was the slowest of any age in any event. I had never reached the finals in a race. This did not bother me much: I was on the swim team with Kris, wasn't I? I was as happy as a shark with a new set of teeth. I was thrilled to watch Kris and my other friends receive their trophies and medals. But after half an hour I got hungry and bored like a typical teenager; I was ready to sneak off to the snack bar. Then to my astonishment, I heard my name called. For a moment I panicked: were they going to give me a joke trophy for being the worst member of the team? The coach announced I was receiving a special award — a tiny gold charm in the shape of a medal — because I had improved my times in all events more than anyone else. In swimming, cutting your time by half a second is significant, and I had improved by minutes.

I cannot remember ever having such ambivalent feelings. Kris's eyes shone with excitement. My friends were cheering and clapping. How could I not be pleased? Yet how could I be pleased? I knew in my guts what no one had ever told me: athletes get medals for winning; handicapped people get special awards for trying hard. Until then, I had felt like an athlete.

In subjective terms my accomplishment in swimming meant that I had worked like a dog, which I expected to do to learn a major new skill. At practice I often put on a sweat suit and high-topped basketball shoes and swam a mile, after I had swum all my races and a mile of regular laps. The best swimmers did this too, and no one made a fuss about it. I often went to bed in pain, but I had been in pain before without being in love. Love beats physical therapy any day.

In objective terms my record-shattering improvement meant that I had advanced from what could technically be called "not drowning" to what could technically be called "racing." I had never doubted that I could do this, but as I stood before my friends that day, I realized for the first time that none of them had thought I could. I understand now that my teammates and coaches were also genuinely awed by the amount of work I had done (they didn't know about the pain). They couldn't imagine working that hard themselves without the reinforcement of winning. I ask you: whose sense of inadequacy was being soothed by that fake medal?

Eventually I bought a bracelet for my charm, but I rarely wore it. I withdrew somewhat from Kris, when she told me she was afraid people would think we were queers. I swam competitively for eight more years and became strong and graceful in the water. However, I owe my real medals and ribbons partly to the fact that competition grew less intense: more and more women quit athletics rather than risk being called "dykes."

As I grew up, I never knew when someone might pity my "deformity" or spurn me for my "unladylike" strength. I learned that in the straight world I would be expected to hide behind a disfiguring facade of femininity, and that among Lesbians I would sometimes find women whose prejudices were more limiting than blindness. Somehow I managed to keep myself afloat in spite of this. Perhaps a medal for not drowning is appropriate after all.

Dykes, Disability & Stuff

'cause we always have stuff to share

P.O. BOX 6194

...

BOSTON, MA 02114

DD&S is a great place to celebrate our lives! We can look toward each other for the radical solutions we need and for the unity to make change happen. Our focus is on the "stuff" of disability in the lives of lesbians. Subscriptions are \$8.00-20 individual, (U.S. dollars, please!) Contributions of art and writing are welcome.

going shopping

i am in the co-op, shopping in my wheelchair. this is a big event. usually other wimin shop for me — it's easier for both me and them. but i love to shop, love to get out, do something outside of my four walls. so my lover and i drive 65 miles to the nearest co-op, where she leaves me while she does other errands.

i tell her not to rush back. i know i can occupy myself for a good hour and a half, checking out all the wonderful food.

people smile and say hello to me. very different from when i'm able to walk, and am thus just another dull nonentity. i don't know how to feel about this. it seems similar to the ways adults often treat children, looking down on those of us below their eye level. it makes me feel incompetent, not fully a person. yet it is hard to dislike friendliness. a nice dykey-looking produce clerk says hello, tells me to ask if i need help reaching stuff or anything.

when i shop on foot, i'm so stressed out. since i don't limp much or use a cane, no one knows that i 'm desperate to pay for my things and get to where i can sit. using my wheelchair is definitely pleasanter. nothing to have to try and explain. no rush. i can relax and enjoy myself.

the organic produce is always so good here. delightedly i stuff bags with fresh spinach, carrots, potatoes. it's a little hard to maneuver my wheelchair *and* the shopping cart *and* get to my cardboard box inside the cart to pull out a bag, mark the price-per-pound on it, put it back in the box filled with veggies. but i'm managing. i block other people's way sometimes and it makes me feel bad — i'm a "problem" again.

there's some fresh gingerroot up out of my reach. i look around for the clerk who spoke to me, but she's not around. although i know it's silly, i'm too shy to ask the other woman, who did not speak or smile at me. it is within my capability to stand up and reach it myself, but this doesn't even occur to me until much later. when i'm in the chair, rolling is how i get around and i forget that anything else is possible.

i have to go to the bathroom. again i look for the friendly clerk in vain. i wonder if this is one of those places where the toilet is for employees only. i bet they'd let me use it anyway. one of the privileges of being in a chair. they don't know what strange malady you have that might just cause you to pee on their floor.

i negotiate a corner — the aisles are wide enough, praise the goddess — past a couple of small kids staring at me. i ignore them, feeling this is as good a way as any to "act normal," as if my using a chair were the unexceptional thing it should be.

in the next aisle are lovely wooden utensils. i want very much to look at a wooden bowl on a high shelf. more than peeing or gingerroot, i want that bowl. i ask another customer, who hands it down. she is obviously pleased to do it and i'm glad i asked.

quite a few people are in the store. i'm looking at pasta and measuring out arrowroot like anyone else, and that makes me feel good. i'm proud to visibly be a disabled person leading a regular life, an example of why stores need to be wheelchair accessible. i also like being living proof that all disabled people are not either old, or male war vets.

in the store's only tight corner, i'm sort of stuck. a man pushes my chair from behind. he could have asked, "need a push?" this happens a lot, and it's nearly always men who assume i need their help and that it's okay to touch me without asking. still, i did need help. confusing. i mutter thanks.

i pass the two kids again for about the fifth time. they are obviously fascinated. i continue to pretend i don't notice them staring, but i say to the younger one, who keeps standing in my path, "excuse me, please." i'm trying to be the rational adult, but it feels like these kids are in the power position and i am intimidated. i remember when i was a kid, how keenly i felt the normality of other kids and their thoughtless cruelties about my body's differences. i also remember deliberately setting a large bowl in the path of my mother's blind friend when i was little. it's been hard to forgive myself for that.

i'm scooping granola. the bins are high, above my head, and it's very tiring to fill my bags without spilling oats and sunflower seeds all over. i realize how near exhaustion i am. my nose is ice cold — the store isn't warm enough for me — and yet under my layers of winter clothing i'm sweating heavily from the exertion

of wheeling around and reaching for things. shopping is beginning to feel more like an ordeal than fun.

and in the next aisle i hear the younger kid ask the older, "what *happened* to her?" mercifully, he is not asking his mother, who would probably hush him up, reinforcing my fear that i am untouchable, unmentionable. his sister says, logically, "how should i know?"

"what *happened*?" i've had adults stare at me and ask that question. is there any way that my situation could be viewed as just what is, rather than something wrong, some horrific tragedy that spoils the rightness of the world? some days, of course, it seems like a tragedy to me, but there are many more days when i go about my business in the ways that i am able to. mostly, i'm glad the little boy didn't ask me the question, because i don't know an answer for it yet, an answer that would come from a different place than the question.

finally, i'm finished. i'm so tired — and, i realize, tense — that i don't know if i can enjoy the dinner out that my lover and i have planned on.

but here, at the checkout counter, all is relaxing. how different from times i came without the chair and stood here filled with anxiety at every extra second it took. now i sit back comfortably while the cashier takes care of everything. even the stuff i forgot to mark prices on. she asks me if i need help getting it all to my car. but my lover hadn't returned yet, so the cashier puts the groceries to one side and i wait.

i think of how things were when i didn't have a partner. what a monumental effort it would have been to shop like this. i would have needed a friend to load the chair into my car, and then at the store i would have needed to wait until i spotted some decent-looking stranger i could ask to unload it. then i'd have to ask the store personnel to put my chair and groceries in the car, and drive home myself — this fatigued. *then* find a friend to unload everything! and if no friend was available, i'd be stuck at home, my "legs" and my groceries imprisoned in the car till i could get help. no wonder that before this lover, i let other wimin shop for me when they would, or i did it myself on foot — quickly, painfully, minimally.

having a lover willing to help out has been a great blessing in

my life. but i am still angry, very angry, that so little in our society is planned to accommodate physically challenged people so that we wouldn't always need to wait for help. wouldn't have to have a lover, or money, or a circle of terrifically able-bodied friends with great attitudes, in order to just live in the world. i don't really like relying on another person for so much, and i have fears about the eventual effects on our relationship.

she arrives; she looks lovely, and i feel suddenly happy again, less tired. she carries the heavy boxes to the car, uphill. rather than her having to push me up the rather steep hill, i decide i'll walk, and she can push the empty chair. it's not a long distance for me, and i don't have much trouble with inclines. standing still, or walking slow, is much harder on my knees. but i dread stepping out (literally) of my role, getting out of the chair under so many eyes, and walking. i feel like an impostor. like the man my mother used to buy rag rugs from because he had a hole in his stomach, and then she would speculate whether he *really* had a hole in his stomach or just used people's pity to sell rugs. i walk out the door quickly without looking back, trying to limp more than usual.

the restaurant is something i can handle without the chair. we walk in and sit down. no one knows anything is "wrong" with me. i feel like i have become a completely different person.

i get up to go pee (finally!) and even though my knee hurts and i have to rush, it seems easier than the whole big deal it would have been in the co-op, with the chair, being so obvious and then having to park the chair outside and walk into the bathroom anyway because almost invariably toilets are not really very accessible. in the bathroom here, i realize how tense and hurried i am. i stay on the toilet for a minute and let myself breathe deeply.

my lover and i sit close together and smile at each other a lot. now, here, i stand out because i'm a lesbian — no one even knows i'm disabled. it feels much easier. not that it's always easy being a lesbian in public. but here, as long as we pay our money, as long as we don't roll around on the floor with each other, everyone will be polite and mind their own business. and it helps that we're both lesbians — i'm too involved in being with her to notice or care what others think. i've also felt this way on the rare occasions when i went places with other disabled wimin.

we set out on the long drive home. i'm full of good food and

fulfilled in general, and i'm very tired. physically tired, of course; but also exhausted from the emotional work i've had to do. i lean back against the seat, remembering the kids' stares and my struggle not to feel freakish. i think of the man's hands on my wheelchair. if only i hadn't been preoccupied with shopping, if only i'd thought faster and said "thanks, but please ask before you touch someone's chair." and then, in the restaurant, curtailing all those feelings and passing as able-bodied — that took energy, too.

i'm tired, yet i want to talk it all out. as my lover maneuvers the car onto the highway, into the dark country night, hesitantly i begin.



Valerie Brown
Jane Philomen Cleland

The Adventures Of An Epileptic

You never know what strange adventures are going to befall you when you're an epileptic. You meet people in the strangest places and the strangest ways.

Eyes were looking at her. Eyes from above. They were brown and blue and brown again...and there were too many to look at all of them. There were shoulders too. Some stooping, some straight. But the eyes were still staring. She did not know whose eyes they were. Among them there was no face she recognised. Not one. Why above her? Why would all these people look at her? A woman...an old woman...an old woman in black. Close...very close to her. Her eyes (she is one of the brown eyes) were just above her, and very close. She was holding her hand and stroking it, she was saying something, something in another language. Then some of the eyes moved. What a strange room. Where do all the coloured boxes come from? None of it made sense. Anna's mind grappled for something, but she didn't know what. None of it made any sense. She felt wet. She was lying in a pool of water. But why? Lying in water? Wetness? Some of the eyes talked above her. There were children, there were grown men and women, and there was the old woman in black with brown eyes stroking her hand. But who were they? And who was she? And where was she? She turned her head to the side and rolled it into cold wetness. Her head returned to its original position. The back of her head was flat against the concrete floor. She turned the other way and saw a row of spaghetti packets, toilet rolls and, just down a bit, tins of cat food. She turned back. Most of the eyes were still there, milling around above her. The fog was still in her mind. It did not know who she was, or who these people were and why she was lying on a concrete floor in a pool of water. The old woman pulled at her, urging her to sit up. She did and saw the open door to the street with the coloured plastic strips hanging down, blowing in the wind. Several children were tangled in the

green, orange, yellow, blue and red strips. Beyond the door it was dark. She turned around and saw the counter of the milk bar — the part where ice-creams are scooped on to cones and milkshake makers stand unused. The old woman in black was smiling at her. Her whole face was wrinkled like a late summer peach. She remembered having glimpsed her through the door behind the counter, but Anna had never spoken with her. The old woman was pointing now towards the door and the eyes of the others followed her hand. The first familiar face — one that she knew she knew though she had no name for it yet — came bustling through the door. She, the face, came over and put a warm arm around her shoulders and moved her towards the door. She wanted to turn and thank the old woman for holding her hand, for caring, but she could not. She felt the eyes penetrating her back as she left.

“How long was I gone? Did I go to buy milk? We didn’t get any before we left.”

“No you went to ring Alva.”

“Oh god, did I finish the conversation? She must think I’m so rude, cutting out on her like that. Oh, I’m so embarrassed. How can I go and buy milk again from them. They threw water over me. I’m all wet. Why did they do that? Oh, what am I going to do? Can you go and ring Alva for me, please. Tell her we were cut off, and I didn’t have any more money.”

“Why not let me tell her what happened?”

“I’d feel embarrassed. I don’t know. Maybe she knows anyway. I don’t want to talk about it with her. If you tell her, tell her that too. Okay? Everyone will be staring at me when I go down the street now. They all saw me. It was like a special attraction.”

“They won’t stare. They’ll forget.”

“What’s that siren?”

“I don’t know, let me look — there’s an ambulance there.”

“They won’t forget. Are there still lots of people there?”

“A few. Look, I’ll go and explain things, then I’ll ring Alva. Will you be okay?”

“Yeah, sure. I’ll be all right here.”

How am I going to face them again? Oh, so public. Why did it have to happen there? Why not here? Oh shit. I’ll have to go and buy things from that other place around the corner. All that

water. I suppose they got frightened — wanted to bring me round. The grandmother was nice, but all those others — just standing there and staring.

Helen came back in. "It's all right," she said. "I talked to the ambulance men — assured them I knew what to do, that you were just tired but that you'd be all right."

"Did you ring Alva?"

"Yes. She said she thought you'd been cut off."

"Well, I was sort of — by myself. So you didn't tell her?"

"Yes, of course."

"Oh...What'd she say?"

"Nothing much, just said it made at least as much sense as Telecom cutting her off ...or the secret service."

She slept heavily. She did not dream. It was like the sleep of the dead. When Anna woke up and remembered the night before, she felt humiliated. She could not think what she might say when she has to go there again. And she knew she would have to — if not today, then tomorrow — whenever she goes the problem will be the same. Should she say thanks?

She went in. For the first time the grandmother was standing behind the counter. She smiled at Anna, showing the gold in her teeth. Anna braced herself to speak. The grandmother called through the door, "*Despina, ela.*" Despina came out.

"Hello. How are you today? Better?"

"Yes, thanks, I'm okay now. And...and...thanks."

"That's all right. We were a bit worried about you. Has it happened before?"

"Yes, it has." But she did not add that it had never happened in a place like that before — never so publicly.

"But you're all right now. That's good."

"Can you tell your mother thanks for holding my hand. And...um...can I have a bottle of milk please?"

Anna was walking back from the Pizza shop, past the low rise commission flats that overlooked her backyard. She was trying to replay what she remembered. There was not much. Not much to go on. A series of images. The eyes encircling her and the

confusion of that first conscious moment. The old woman's hand on her hand, the sense that someone — whoever she was — did not wish to harm her. And then the image of being dragged home, corpse-like, along the street. And yet she knew she walked.

She looked up from her reverie. Two little boys were standing looking at her.

"That was funny what you did the other night falling over in the shop," said one of them. The one she recognised.

"Yes," she said, "yes, I suppose it was."

She tried to say goodbye brightly, but it fell weakly from her lips, as she turned to go home, to get away from someone else's perception of her.

Anna is not unusual. She just has unusual friends. Unusual to some people, that is. They seem very ordinary to me.

"Listen to this: 'Pornography is the fantasy, rape is the practice.'"

"Well that about sums it up, doesn't it?"

"Yeah, but how can we stop it?"

"I don't know, but I do know that we've got to help some of the women they're practising on."

Anna was one of six women sitting in an upstairs room of a Collingwood shopfront they used as their base for a Rape Crisis Centre.

"You know that woman who rang yesterday," said Anna, "The seventeen-year-old from the country who came in here a few months back, well, her case is coming up for committal next week. I want to go along to the court. Does anyone want to come with me? I don't really want to go by myself."

"What happened to her?"

"It's almost a textbook case — the sort they like — she was raped in one of those lanes off Little Bourke Street in the middle of the day by a bloke with a record. He was out on bail at the time.

"What day is it on?" asked Jane.

Anna, who was sitting on a mattress on the floor, threw up her arms and gazed blankly towards the middle of the room.

Jane tossed a box of matches at Anna. "Hey, dreamy, when's it on?"

Anna fell sideways, knocking her knuckles against the brick wall as she went.

Jane leapt to her side. "Oh, god, what've I done?"

"Looks to me like she's having a fit," said Sarah calmly. "I knew a girl at school who had them."

"What do we do?"

"I don't know."

"Why don't we call Lisa?" offered Wendy, "She'll know what to do."

Jane had moved over to the wall and was cradling Anna's head in her lap. "I thought I'd knocked her out," she said to no one in particular.

"No it missed actually and it whizzed past her ear," said Julie. "I noticed because I thought what a good shot. Anyway I think she was already out to it by then. Look at her hand."

Julie lifted Anna's hand and pointed to the grazed knuckles. "At least she didn't have far to fall."

"Yeah, she'd have come down with a real thump, I reckon, if she'd been standing up."

The doorbell rang. Wendy went to open it for Lisa.

Anna opened her eyes and couldn't work out where she was. She looked at each woman without recognising any of them.

Lisa walked in with her little black bag and looked at her. "How do you feel?"

"Oh, all right," mumbled Anna, "Considering. A bit tired though."

"Has it happened before?"

"Yes, a few times."

"How long did it last?"

"Ten minutes."

"No, it was more like two minutes."

"I'd reckon about five minutes."

"You lot wouldn't be much help in a court of law."

Some people just don't get it. Some people think you've knocked your head and fallen unconscious. Well, I don't suppose you can blame them — it's not always the first explanation that comes to mind.

Anna walked her bicycle out the front door to go to the conference. She raised her leg over the bar of the bicycle and the

whole thing collapsed. She lay in the centre of the road, the bicycle quivering above her.

By the time the neighbours reached her, she was still, and so was the bicycle — except for the mad spinning of the back wheel. They had worried looks on their faces as they carried her through the front door and settled her in a chair.

Mrs. Bernadino went to make coffee, while her husband sat and kept an eye on his strange young neighbour.

"Do you think she'll be all right?" he shouted. "That was a heavy fall she took — didn't seem to be able to stop herself. I hope she hasn't got concussion. I don't fancy spending the day at Out Patients."

Mrs. Bernardino came in and stood while she waited for the water to boil. "I think she'll be all right," she said. "They're no marks or grazes on her head, just that nasty graze on her elbow. And her eyes are a bit glassy. Are you all right, dear?" she asked.

Anna nodded.

"Good. You watch her Joe, while I get the kettle."

"Now dear here drink this, the coffee should make you feel a bit better. That was a nasty fall you took."

Anna nodded again, frowning. She drank slowly. Where'd this coffee come from? How'd I get here? What fall?

"What fall?" Anna asked.

"You fell off your bike. Don't you remember?"

"No."

I don't know these people. I wonder where I am. Who they are. They seem to think I know them. But I don't. She looked at the cup of coffee. My god, how long have I been here? What have I said? The coffee's half gone. What happened? I don't remember getting on my bike, let alone falling off it. Shit. Well, I suppose they just saw me fall and assumed I'd knocked myself out.

"Did your foot miss the peddle?" asked Mrs. Bernardino.

"I suppose so, I'm not sure." I've got to go. I've got to get out of here.

"Are you a student?"

"Yes."

"Probably too many late nights — you should go to bed early instead of studying so late."

"Mmm," answered Anna, trying to be polite, finishing her

coffee, standing to go. "Well, I'd better go, I'm already late." Late for what, she wondered. "Thank you for the coffee. It was nice. I feel a bit better now."

She headed out the front door and was surprised to see her house next door. She hadn't realised they were her neighbours. She wheeled her bicycle to her own house and leaned it up against the fence.

"I just have to get a few things," she added. "Thanks."

Anna went into her house and rummaged through her bag to find out where she was going. The conference programme was there. For a few moments she was confused, not remembering. Then she remembered the workshop she'd been in the previous day. All those amazing women — writing books, directing plays. All so talented. I'd better go. But I wish my head would stop hurting. She put the programme back in her bag and left for the second time.

Sometimes you find yourself in places you wouldn't have predicted. You can finish up being with other strange women.

Anna woke in a strange bed. Her mind was blank. Empty.

"Where am I?"

"Don't you know?"

"No...I...I don't." She scoured the walls for something familiar. She did not recognise the room. A woman bent over her, half naked.

"How?...I don't understand."

"You had a fit. Do you remember anything of last night?"

"No."

"That's a pity, it was such a good night."

"Why? What? What happened?" The emptiness pressed her back against the sheet.

"You decided to stay the night. You came to dinner and then you were too drunk to drive."

Some of it was emerging from the empty blackness inside her head. An image here and there that she could barely grasp.

We were lying on the floor in front of the fire, both of us drunk from too much wine.

"Do you remember what we talked about last week?"

"Yes."

"Well, it's all changed. We've decided to split up."

"Is that a you, plural, decision?"

"No, not really."

"Why do you think she wants it to finish?"

"Boredom. I don't really know. I think there are things she isn't telling me. She says she wants to be celibate. Basically, she's not interested in me anymore. "

"And what about you? What are you going to do?"

"Oh, there are several possibilities...and you're one of them "

She reached out and touched my hand lightly. I leaned over and kissed her.

"I don't know about this. Isn't it a bit soon?"

"She can hardly complain."

"But what about our friendship? I think you should go home."

"I'm still too drunk."

We lay there, discussing the pros and cons of sleeping together, for two hours — occasionally touching and kissing. Her hand brushed against my breast, as if by accident. I pressed my tongue against her neck. We embraced.

"I should ring her. Or she'll worry."

"What about tomorrow?"

"I'll tell her we slept together."

"You don't have to tell her."

"Yes I do. She'd know anyway."

I was about to stand up.

"Are you sure?"

"Yes, I'm sure."

I rang.

She removed her clothes. I would have liked time just to look at her, but she dove into bed. Her skin sagged a little. Nicely. I crawled in beside her. The feel of nakedness...it had been so long, months.

"I don't know if I can remember how..."

I realized that for her it is years. She turned to me.

"When did the possibility of sleeping with me first occur to you?"

"The first time I came here for lunch. I can even remember what we had — parsnip snoup, I mean soup, and prune tart. I don't remember the main course. What about you?"

"Oh, a while ago."

Our hands moved. I could feel my wetness seeping. The unfamiliarity made us tentative. Tongues pressed against lips, teeth, tongue, nipples.

The silence was broken by breath drawn heavily through nose and mouth. From time to time we reached for water to moisten the alcohol dryness of our mouths. Cool wet kisses.

Her nipples rose to my touch. Her hair and cunt were wet. I pressed my legs between hers. Clutched at her cheeks. I plunged my fingers into her. Our bellies connected.

We rested.

"I don't know whether I feel adulterous or incestuous."

I am silent with my own confusion.

"I don't suppose it matters really."

"Do you think we'd be here if we hadn't been drunk?"

"No."

"And why didn't we speak of this on Tuesday?"

"Because it was daytime, and we were sober."

We began again.

The night drew on.

We stopped and started again and again. I can't remember how many times.

"You sex starved thing."

We began again.

"I'm at my peak. Thirty-six. It seems a pity to miss out at such a time."

My finger ran tightly over her clitoris.

"You *are* good."

"I'm glad you think so."

She was sitting, in the sun, on the edge of the bed.

"Are you all right?"

"Yes. I can remember it now. I still feel disoriented though."

"I didn't know what was happening. I was too slow to put something in your mouth."

"It's not a good idea. It's better just to hold the person and allow the fit to proceed. I always bite my tongue anyway. See." Anna stretched her tongue out to where the teeth marks were visible.

"How long did it go on for?"

"It felt like hours, but it must have been only a couple of minutes."

Thoughts straggled into place. The picture was nearly complete. Memories of pleasure swept through her. Anna reached for her again.

It's not just strange houses you find yourself in. It's strange predicaments.

She raised herself unsteadily from the floor and headed out the nearest door. A door was open and she walked through it and climbed into bed. She slept.

When she woke she lay there wallowing in the sun. She opened her eyes and looked around the unfamiliar room.

How did I get into a room like this? It must have happened again.

She sat up in bed and looked out over the harbour. Sydney?

Flopping back on the bed she tried to work out how she got there.

I'll ring home. No. Can't do that. Can't remember the phone number. There must be a telephone book here.

She dialed 0175.

"Hello. Melbourne. Kin. Collingwood. Thank you."

She dialled again.

"Hello. I think I've had a fit. I'm in Sydney, but I can't remember why or how long I've been here or where I am in Sydney. I think I'm in a hotel... All right. You ring me back. Do you have the number?...Okay."

Anna dozed as she waited for the return call. It seemed to be taking a long time to get through. She got up to look for something in her bag, hoping for a clue. She opened the cupboard door. And nothing in the drawers. It didn't make sense. No clothes. No bag.

No books beside the bed. She got back in the bed and pulled the covers up — with a dawning suspicion of what might have happened.

Oh well, I suppose they'll find me. I can't really go anywhere without anything on.

When the knock came, she called, "Come in."

The housekeeper and a boy walked in. "Hello, I'm epileptic and I seem to be in the wrong room."

"Are you all right?" asked the housekeeper as she handed her a towel. "This is room 806, you're in 805."

They walked down the corridor to 805.

"How did you know where I was?"

"Your friend rang and when she didn't get an answer she thought you might have had another fit. So she rang the desk."

A few minutes later the phone rang again.

"I must have walked along the corridor naked."

You get used to the unfamiliar places and after a while you learn to devise ways of working out where you are. It takes a lot of stamina not to panic sometimes.



Spike and Dome Instant
Max Hammond Dashú

Orig. published in *Close To The Truth*, KIDS Project Press Publications, 1989.

Diane Hugs

Who Needs a Perfect Body?

She approached me timidly
like the first time woman touches woman
this was new for her
making love to a disabled woman
so many questions

touches soon gave way to answers
although my body has lost a lot of function
there is still a sexual fire ablaze
no wrapping of legs around her
within my warmth she wraps herself

touches my body can not feel
the love becomes another kind of energy
rushing up my spine, thru my head
filling me to explosion with warmth

the mutual exploration of sexuality
flooding each other with the energy of love
finding no limits to my love
flowing out of heart and hand
flowing up through her body

who needs a perfect body

Orig. published in *Close To The Truth*, KIDS Project Press Publications, 1989.

Untitled

I was born without a left hand or arm below the elbow. When I was two years old, I was taken to Shriners Hospital in New York. I remember a room with little chairs, my size chairs, and tables. A big, painted wooden shoe. Flat, like an oversized child's puzzle with raised metal grommets and laces on which I was to practice tying shoe laces with my new artificial arm. I remember sun coming in through a window, feeling small, and silence. I don't believe it was silent there, but when I recall it, that is the feeling. I don't remember the first time they stuck my arm in the warm, gooey plaster and wrapped it with ace bandages, smearing plaster and wrapping, molding the cast to my arm as the plaster went from warm to clammy cold. I don't remember the first fitting for straps and the endless measurements and opening and closing the new rubber hook.

Every 4-6 months, until I was 16 or so, I went to a Shriners for measurements, adjustments and plaster casts. As fast as kids outgrow shoes, they outgrow prostheses. I would get a day off school and mom would take me to Shriners. I hated going. I hated feeling different, hated the other kids, hated being lumped together with them. We were "crippled." We went to Shriners Hospital for Crippled Children. There we'd be in the halls lined with chairs, our parents, mostly moms, looking pained and ashamed, trying not to stare at each others' children, but not successfully concealing their morbid curiosity. I recall my mom and another woman looking at a child with no arms, just some fingers at his shoulders, and shaking their heads, saying "it really makes you count your blessings, doesn't it?" It could be worse. It could be *that* bad. I remember a child on a table in a body cast, screaming in terror over the noise of the power saw as it cut away the cast.

We sat in a hallway lined with chairs and waited for interns to take our measurements. In a room at the front of the hall sat the doctor-gods. Flanking them were rows of chairs where the student nurses, physical and occupational therapists, etc., sat. One by one our names were called and we would walk, limp or roll

down the hall to them. Everyone watched. When we got there, the doctor-gods would examine us, turn us this way and that, and then take questions from the assembled interns/students. They would make a few comments into the dictaphone. Then we were dismissed; we could go get our clothes and leave, as the next one was called.

It's truly hard to say...what it was like. Being discussed and examined by the doctor-gods and students was humiliating. Taking off my shirt to show them my arm, the straps across my back and under my arm ... being stared at by all the parents, the pain and the shame of the parents, of us kids, just hung in the air. How defeated I felt as we stood at the nurses' station making the next appointment. I remember the pavement in that parking lot, remember breaking for the car. My mother sighing, exhausted. I repeated this ritual for so many years. Until I was a teenager, until the humiliation of taking off my shirt and exposing my young breasts, my bra, was too acute. Until they finally acknowledged that I was too old for children's clinic. And so it ended.

Growing up, my family called my artificial arm my "helper." That was the name we used to refer to it. Like "Barbie." "Mom, seen my Barbie?" "Mom, seen my helper?" I didn't really know the word "prosthesis," which is kind of a mouthful. In front of company we said "artificial arm." I put it on when I got dressed in the morning and took it off when I undressed at night. It was never a consideration that I might go without it. On the hottest summer days, when the sweat stuck the straps to my back, and the chafing from the strap under my arm made me crawl the walls with rage and discomfort, it was never a possibility. Certainly never in public. Unless we were going swimming. Swimming was one activity that *required* removing my arm in public. The process was agonizing. Where to take it off? On the beach? Nowhere to hide, there. I preferred the public bathrooms, in a stall where I could stuff it in my beach bag and put things on top of it, drape a towel over my arm and pile everything up in my arms. No one would know until I got to our blanket on the sand and had to unburden myself....

The word "deformed" pounded in my brain, though in truth I thought my hook far uglier than my arm. I hated the shiny metal hook that in later years replaced the child's rubber one. Hated

how it stood out, hated it and hid behind it, for it had become my armor and I felt vulnerable without it. This thing that was supposed to make me more acceptable, help me function just like everyone else. My "helper." I hid in that device and hated it, but I was unable to conceive of not wearing it. I felt it would be far worse for people to look in horror at my real arm as they did at the hook.

The compensations were endless, long sleeves in the heat of summer to conceal my arm brace, high necklines to hide my shoulder straps, nothing too sheer, nothing too thin — nothing that would draw attention to me. I stuffed my hook deep into my jacket pockets when I was on the street, hoping to pass, and once safely at home the final act of frustration, anger and pain culminated in my ripping "my helper" from my body and flinging it against the wall.

I used to believe I owed an explanation to whomever demanded one. I felt fearful, intimidated, ashamed, out of control and outraged, yet "what happened to your arm?" was not a question that I could choose to answer or not. I was a freak, an outsider, an "other," and the world made it very clear that I owed them an explanation. I was also a little girl who was chased home from school with taunts of "Captain Hook!" ringing in my ears, the object of whispers, stares and laughter. "Don't let *her* play, she'll pop the ball with her hook!" The dominance and submission in the abled/disabled relationship was/is very powerful. This harassment is a fact of my life. I've heard "mind if I ask you a stupid/personal question?" from sensitive lesbian psychotherapists, suburban housewives, boys in gas stations, salesclerks, doctors, joggers, dykes in bars and so on ad infinitum. I detest it, it hurts. I feel like an object of curiosity, not a woman with a head and a heart and feelings that should matter.

My mother sent me a *Life* magazine article on the movement to bring myoelectric arms into wider circulation. The heading reads, "For children born with missing limbs, myoelectric replacements offer a chance to lead LIVES THAT ARE WHOLE." Myo's use electrodes to transmit impulses (caused by flexing muscles in the arm) which open and close an artificial hand. The myo's do not have the confining figure-8 straps which characterize the hook. The circuitry is encased within the forearm, and it is

made to look as much as possible like a real hand. They cost between \$10-15,000. During the later years of wearing my hook, I really wanted one, but could no way afford it.

The article is laced with anecdotes and commentary from myo users, doctors and prosthetists who view the hook as obsolete. The emphasis is on how much like a real arm it is, with "skin folds," airbrushed veins, etc.; how passing as two-handed makes life so much more comfortable for the wearer. "In cool weather, when long sleeves are worn, most people don't notice it's not a natural arm." "Now that I have a myo, I've stopped getting those double glances. I don't feel like the Elephant Man anymore." The medical establishment promotes identification with the arm to the extent that the wearer is supposed to perceive her/his self as actually having two hands. Prosthetist Thomas Habam believes that "the sooner babies with defects get myo replacements, the better. Under one year is not too soon. You want them two handed when they are progressing through the natural stages of development . . . *early on, you want them to see 10 fingers.*"*

These disabled kids are asked to participate in a conspiracy that distorts reality and promotes a profound level of denial and self hate. Why? Who does this really benefit? This line of thinking enrages me. I grew up with a huge amount of alienation around this part of my body. And I was never asked, as these kids are, to identify the artificial arm as "me." As it was, on many levels, it became so tangled with my self image that I could barely separate "it" from "me." It is commonly understood that a child given a prosthesis "too late" in life (after 4 or so), will have adapted to the point of rejecting it. The medical community frowns on this. But adaptation is a way of life when you are disabled. I have to adapt to use the arm as well as to go without it. Early introduction of an artificial arm is not merely to ensure facility with the device. Built into the concept of prosthetics is the need of a fearful and cowardly world to avoid what is different and thus threatening to it. So we are compelled to cover up, to hide our "defects" so that we are less offensive to others.

It is a conflict. Many times, I long to and do try to pass. I don't always feel up to the challenge of facing the world. It's hard. Hard to go out in public. To choose where to go, where to avoid, how

* My emphasis

to stay present. Aware of when I'm getting out of my car or crossing a street and I'm being watched. Sometimes for a brief time, people can't see my arm because something is blocking their view; they're looking at me and I'm thinking, steeling myself and thinking, any minute now they'll notice. If they are thinking I'm pretty or they like what I'm wearing or they're just idly staring, any moment now it will be smashed. And I cringe inside.

Acknowledging these feelings, let alone figuring out healthy ways of dealing with them, has been a profound task. I had a legacy of denial passed from culture to parent to child. From covering my arm up with a blanket when I went out as a baby, to reprimanding me when I once wept that I was "crippled" ("You are *not* crippled," my mother corrected. "You are *handicapped*."), my parents used denial as a tool for coping with a reality that they could not face, that they felt I could not face. And so I grew up being told — you are no different than anyone else. You have to do some things differently than others, but you can do anything anyone else can do. Don't cry, don't be self-pitying, the taunts and stares are the products of ignorant minds. Chin up. From my father I got: you are a product of me, you are intellectually superior. You may have half the fingers but you have ten times the intellect. Prove it. Use it. So I learned to deny and deflect reality when it pressed in and to intellectualize feelings.

Years later, with a dyke therapist, I did finally tell the truth. It was not fun. It made me crabby and angry and frustrated and vicious, and it hurt terribly. I hated the world, the lesbian community, everyone. The relief in saying was not sweet; in fact, it scarcely felt like relief at all. I said the same things over and over until I hated myself for droning on, hated her for not turning it in a different direction, for not fixing things, hated the lump in my gut for never yielding, the facts for never altering, the events of the past for never undoing themselves. I am exactly what I'd been taught to deny. I will never wake from this dream. It is not a dream. There will never be the "*even 5 minutes with two hands, please, god*" that I had wished for. Period.

Yet there has been much recovery. Sometimes I catch myself doing something — like being without my fake arm in a straight work environment — and it pulls the breath out of me for a moment, I feel so proud. Other times it's back to hell again. I went

to the mall in a short sleeved shirt a few weeks ago, and it was a huge mistake. I burned with shame and self-loathing all the way through and out the door. But I still feel proud of myself and special. I have felt very oppressed by the use of "special" — I have been fed "special" in a pitying, pious, god-loves-you-that's-why-he-singled-you-out way that has been painful and destructive to me. "Special" has oozed condescension and superiority, as though the bearer is also congratulating her/himself on having personally escaped such a fate. But I am special. There aren't lots of me everywhere. My first woman lover was the first person who ever suggested I go without the prosthesis. She liked my arm, thought it was cute. "She has a dimple," she said. And I thought, "Yeah, she does, I do." My arm is soft. When I was a little girl I would suck on it, alternating with my thumb. So would my little sister. We'd lay down for our nap and she'd reach over and grab my arm... as a child, that was the most love and acceptance I'd felt from anyone. So yes, I feel special. This life that I have made feels special.

I feel gratitude now with the grief. For my spirit that would not accept the culture's definition of me as a script for my life, for knowing finally that their beliefs are not my beliefs, their vision is not my vision. For the self-love that soothed and sustained me when I couldn't even admit its existence. For my unwillingness to accept powerlessness in the face of abuse or the damage as irreparable. For the courage to find my way to a process of healing. Gratitude for the women in my life who have reached out with love, support and open hearts.

My friend S.J. grabs my arm in one hand and my hand in another and we stand facing each other that way, swinging our arms back and forth and chatting. It's great. It feels like — "I like you, I accept you, you are wonderful just the way you came to this planet." There is a quote from the great book *No More Stares* that has special relevance for me. "I don't want you, they don't want you, nobody's gonna want you. At a certain age in my life, it dawned on me — well, I want me. If on one else on earth wants me, I do."*

I do want me, finally.

* Babyie, in *No More Stares*, published by The Disability Rights Education and Defense Fund, Inc., Berkeley, CA, 1982, p. 102.



Max Hammond Dashú

Barbara N. Dinnerstein

Hey, Who Turned Down The Sound?

I was about eleven years old. I was in the fifth grade and my whole class went in to the nurse's office for our annual physicals. We each looked at the eye chart and had our hearts listened to and our hearing tested. Well, we were all lined up alphabetically and I was fourth. So I got to watch all the kids before me and I saw them all put on the funny headphones that squished their heads tight and then the nurse would tell them to listen and when they hear the beep, raise their finger.

The three in front of me did just that and the nurse said good and then they went to the next part of the physical. My turn came and I thought it would be as easy as the other kids. I complained about the headphones and the nurse ignored me, everyone knew I was a chronic complainer. When I got the damn things on I waited for the beeps, I really waited. I thought the nurse was punishing me and not making the beeps so that I'd have to wear the headphones longer. I saw her moving the dials on that little "Belton" machine.

A few minutes went by and I still didn't hear anything. I began to get a little scared. The nurse looked up from her machine and told me I had better stop fooling around and pay attention. Then she took the headphones off me and listened to them herself. Meanwhile all my classmates began to stare at me, like I was crazy or something. The nurse told me to go back to the classroom and to wait for her to come and get me. I walked back to my class all by myself, thinking I had broken the machine because I was so fat. I was trying to think how I could have broken the machine.

Back in the classroom I put my head down on my desk and cried. I wanted to run away but didn't know where to go. About a half an hour later my classmates came back from the nurse with our teacher and they all laughed at me and said, "Dinnerfat broke the machine, Dinnerfat broke the machine."

My teacher told me to go back down to the nurse's office. The nurse had me put the squishy headphones on and listen, but

before she put them on me she said I had better stop playing around. So we tried again and this time I still didn't hear the beeps and I got really scared. We did this for what seemed to be the entire afternoon. Finally she told me to take this note home to my mother.

When I got home, I found my mother in her usual place in bed. She was just laying there with her box of Shop Rite chocolate chip cookies and Divorce Court on tv. I gave her the note. She read it and started to cry, and then just told me to go downstairs and take care of my brother.

The next day my mother came to school with me. My mother was one of the major embarrassments of my life; she never bathed or washed her clothes, so she would put on tons of perfume and a smelly dress and bright red lipstick. Anyway, we got to school and my mother and I walked down to the nurse's office. The nurse put those squishy headphones on me and we tried the test again. This time I still didn't hear the beeps. The nurse told my mother that she thought I was losing my mind or my hearing and that she should take me to a doctor to find out what was going on. My mother started to cry and said, "It's the Dinnerstein Curse. It's your grandmother Rosie Dinnerstein's fault."

I went to see Dr. Glassgold who took care of my Uncle Morris. My Uncle Morris lost all his hearing when he was something like 23. His nurse took me into this tiny room with all these ceiling tiles on the walls. The room looked like it was one of those big refrigerators that they have in the grocery store. I was afraid to go inside. In Hebrew School we had just started to talk about the Holocaust and how Jews were forced into big rooms to take showers but instead were killed. I didn't know this doctor and I certainly didn't trust my mother to protect me, so I was afraid I was going to die in this strange refrigerator.

Once in this room, the nurse put on those same squishy headphones and told me to look through the mirror at her and when I heard the beeps I was to raise my hand. The lady left the room and shut the door behind her with a big thud. I felt the air sucked out with her. But she just sat down at this huge machine on the other side of the glass and smiled at me. Then I started to hear these strange sounds like beeps and boops. I kept raising my hand, right for noise in my right ear, left for left.

I thought it was kind of neat and really began to have fun myself. I was getting all this attention from the lady, from my mother, from the doctor. The best part was that my brothers and sister weren't there and my mom was out of bed.

The test was over and they let me out of the refrigerator and my mother was waiting for me. When the doctor called us in, I got to sit in this chair that looked like it belonged on a space ship. He looked in my ears and throat and took a tuning fork and tapped on his knee and put it near my ear and asked me if I heard the noise it made. I nodded my head, yes.

He told my mother that I had a "progressive binaural sensor hearing loss." I had no idea what these five big words meant. But I thought it was really neat that there was something that was going to make me different from the other kids, other than being fat and dirty.

The doctor told my mother that there was nothing he could do for me; hearing aids wouldn't help me yet. The only thing he could suggest is that I sit in the front of the room and get preferential seating. I didn't know what that meant either, but if it was like prefer, like I prefer chocolate cake over liver, I was all for it.

Well, that was the end of that, I thought. No more squishy headphones, no more stupid beeps, but I did get to change my seat and sit in front of the teacher's desk. I felt like I was going to finally get noticed. I thought that I was going to be special because I couldn't hear the beeps. That was great. I mean, who needed to hear a bunch of stupid beeps anyway?

from My Worst Fears

My doom comes on slowly
slipping softly on stealthy feet
decibel by decibel
it comes. ...

Long days of boredom and terror!
I cannot see and couldn't hear
if someone were breaking in this very minute.
Twitching, awaiting a man's cold fingers round my neck.

I've watched it happen to others
who must trust their lives to those with no time
to learn their language.

Eating slow dinners alone in restaurants,
can't eat and "talk" at the same time.
Sitting still and frightened in a crowd. ...

Always waiting, isolation, freak, reduced
to polite dependence on untrustworthy others.
Embarrassed hoping, pathetically grateful for the smallest crumb.
IT IS DANGEROUS TO BE ANGRY!

Rejected by the deaf and the blind
for I may become deaf and am already blind
embodying the worst fears of both.
They are my worst fears too.

About My Worst Fears

In January of 1987 I finally decided to stop putting off a visit to the doctor about my hearing. I didn't want to admit I was having any trouble hearing but got concerned when I started having trouble judging the direction from which cars were coming. As a totally blind person, I use my hearing for almost everything from telling when water boils to finding out if it's windy or raining. I use it to read talking books when no braille is

available and to judge traffic when crossing a street. So I was scared when the doctor said I could use hearing aids and that I have a binaural (both ears) sensory-neural (nerve damage) hearing loss which would get worse as I get older and could not be stopped. He said it was a minor loss I was experiencing compared to what he often saw. But he was talking about people with sight....

When a family member, who speaks softly and fast, requests that I put on my hearing aids I feel threatened and angry thinking "I don't want to, I don't have to have them all the time yet, why can't you just speak up a little? Why do I have to make all the adjustments?"

...Even without formal training most sighted people experiencing a mild hearing loss will begin to watch faces to supplement what their ears tell them.

It is VERY IMPORTANT to me that all who read this know that I am NOT trying to describe accurately the lives of womyn who are visually and hearing impaired. I know there are womyn with hearing and visual impairments who live full rich lives. I am only trying to deal with my fear. When I say in this poem "I've watched it happen to others," I speak of people who were clients of the rehab. agency for which I used to work. They, like me, were struggling with hearing and/or visual problems as new events in their lives. I do not intend in any way to discount the capabilities of womyn who have hearing and vision loss. I only describe the first step in facing my own situation, admitting and sharing "My Worst Fears."

Quality Of Life

As a woman severely disabled by chronic illness, quality of life is a continual struggle.

When I first became ill six years ago, I was convinced I'd get better and return to what I thought of as a normal life. All the doctors assured me of a cure in six months, a year at the most (they couldn't conceive of not being able to fix a patient.) As the first two years went by and I slowly came out of "plausible deniability," the reality of my life put me on the edge of despair. The realization that I'd never work a paying job again, not go to acupuncture school, dance, theater, or trapeze classes, have little or no political involvement or social life, plus the inability to depend on being well enough to plan ahead for even a day, made life look so bleak, it didn't feel worth living.

Since then, the quality of life looks different each year. It keeps peeling away layer by layer, like an onion. What felt absolutely impossible to live with three years ago has become everyday. Five, even three years ago, I thought I'd slit my wrists if I knew for certain that I'd never "get better." "Getting better" is too broad a concept to think about any more. "Get better" meant "cured" and was the whole onion: round, shiny, smooth, all layers intact, no bruises, cuts or peeled skin. I had to admit to myself that I wasn't going to "get better" in that sense. I might improve, I hoped I would, but I'd never have the whole onion again.

What is the quality of life? How do I figure out for myself when life is no longer worth living? I continually ask as each layer of onion peels off. The third year I suddenly became dramatically allergic to everything, making it more and more impossible to leave my home. I became allergic to all but seven foods, and required oxygen and a wheelchair when I did venture from my home. Debilitating exhaustion kept me in bed seven and eight weeks at a time.

This was the year I was forced to accept the fact that my illness was here to stay. I not only spent the year grieving, but assessing the quality of life. Up to that time, I'd defined it as the whole

onion, and assumed I'd get it back. Now, I looked forward to a week out of bed every seven or eight weeks, occasional relief from migraines, nausea, chronic all-over body pain and debilitating weakness. Participating in creative groups when I could, visiting friends, going to the park, marina, and more rarely, a Lesbian event with my lover, helped to make life worth living.

My fourth year I rarely had energy to be out of bed. The majority of that year I spent in cellular exhaustion (lack of enough energy to roll over.) The migraines, other assorted splitting headaches, nausea, aching muscles, arthritic joints, painful scoliosis, allergic reactions, and everything else that made me miserable, continued to become more severe. I spent that year on the edge of suicide. I'd been stripped of the things I could do the year before, and they'd become my new concept of quality of life. Only the lack of energy to get out of bed and find something with which to kill myself saved me.

As each layer is scraped away, the quality of life is defined by smaller things. The fifth year, I decided I couldn't live through another year of cellular exhaustion. It became my bottom line. A few days out of bed each month became the new criteria. I also wanted some measure of relief from severe brain dysfunction, the constant fogginess and the horrible headaches. At least one "day off" from these symptoms every couple weeks was necessary to make life bearable. If I could manage to do art once in awhile, write a new piece occasionally, and at least talk for part of the date time with my lover, then life could still be satisfying.

I got a break from cellular exhaustion a week here and there from April to mid July of the fifth year, then life became the same as the year before. The improvement from April to July kept me from total despair. Only eight months of continual cellular exhaustion, versus the whole year, was a reason to keep living.

From July of the fifth year to now, another year has passed, more layers have been stripped away. Mostly, I average one hour out of bed a day, which means eating and using the bathroom. It's been two years since my brain has functioned well enough to write anything except a few love poems to my lover. Writing this piece has taken every bit of energy that I've had out of bed, much time to complete, overwhelming fatigue, extreme headaches from all the thinking, and extensive editing from Barbara Ruth.

Most of the time, I'm too fogged out to even think. I've given up identifying as a writer. One more piece of the quality of life drops away.

The brain dysfunction is progressively worse, making it extremely difficult to do anything but lie in bed. In the past year, I've had a total of maybe three weeks of ability to read, but I don't remember what I read. Reading had always been a major pleasure in my life. As my brain functioned less and less for reading and writing, I replaced them with art. Painting didn't hurt my brain as much, or fatigue it in the same way reading and writing did. Being able to do art once in awhile added to my finding life enjoyable. Now it's almost a year since I've been well enough to do any art work. Another part of my quality of life peels away.

As the years go by, I talk less and less on the phone. It's incredibly draining and thinking causes little explosions in my brain. Mostly I don't remember much of what I talk about in conversations. The phone had become my access to friends, since very few people come to my home. As I lose the ability to communicate by phone, my isolation becomes more complete.

Before becoming ill, I was very active. I had friends, I was creative, I read. Now, the tv consumes most of my waking hours. It takes little brain, or physical energy, I can blob out on it and be less aware of how terrible I feel. It's extremely boring and the lowest on my list of things that make life gratifying, but it's what I'm left with.

Increasingly, my life is bed, bathroom, eat; bed, bathroom, eat. As I lose more parts of myself, my perception of quality of life is continuously challenged. Throughout the process of defining quality of life, I've been up against the cultural values of production. People who work for pay are more valuable than so-called non-working people. Our culture views chronically ill people as non-producing; therefore of no value, worthless, a drain on society. But I don't want to confuse the quality of life with my personal worth, or my right to exist, or having my basic needs taken care of. It's taken me years to separate these.

The work ethic of my family and culture was well ingrained in me. I felt worthless since I couldn't contribute in a culturally defined way. At first I couldn't work at a job, then, more importantly, I couldn't contribute by belonging to political or creative

groups, then my ability to contribute by writing was gone, and now I can't even care for myself. I still haul myself out of bed to dress, go to the toilet, eat, and bathe every two weeks, but rely on attendants to do everything else for me.

It's taken this search for quality of life to separate my value as an individual no matter how little I can "do," from what I feel gives quality to my life. Quality of life isn't about what I can "do" or if I can "work" or not, it's about enjoyment of life. It's about having something in my life that gives me pleasure, enough pleasure to want to keep living. Now that I don't rely on what I can "do" to define my value, I've found other things to give life meaning. I've had to turn the little things that I've enjoyed since childhood into my new criteria. Hearing the robins, stellar jays and their friends as I wake up each day has been one of my reasons for living this past year. All the beautiful swaying trees outside my windows are another. Having the energy to sit up in bed and watch the sunset puts enough joy in my life to want to make it to another day. As I lay in bed month after month, I get pleasure from looking at beautiful crystals and stones on my dressers. Paintings clutter my walls. Having the beauty of the stones and paintings surround me is part of my new definition.

Shedding these layers, coming to rely on the birds, trees, sunsets, crystals and watercolors as quality of life is not a great spiritual revelation for me. My illness isn't about learning these lessons. I'm simply a woman with few choices left. I'm not courageous and brave, as the able bodied tend to think about the severely disabled. Nobody volunteers to be disabled, like they do to climb sheer cliffs or swim the English Channel. I'm not anymore enlightened than anyone else. I just don't have many more layers to peel away.

What will the quality of life be if I lose my one hour of energy a day, if I go through another whole year of lying in bed too exhausted to breathe or roll over? If the pain and exhaustion and splitting headaches and dozens of other symptoms drown out the joy of birds and sunsets and watercolors, will that be the bottom line? I don't know. Perhaps. Perhaps I'll discover, as I've been forced to these past years, that there's yet another layer to peel away.

Bump

I.

The confines of the nursery were at all times
secure:

The yellow walls warm with Renoir's little girls
The solid oak chest my mother would lean her back against at
night, as she

held me in her arms, her face in my neck
The wind chimes pealing like a girl's uncertain giggle in the
perpetual breeze.

With only the crack of light under the door to guide her
my mother wandered my room at bedtime, pretending to trip,
to knock up against furniture by accident, saying bump
into my neck already full of kisses, bump
bump.

And this is what I learned:
That danger is only what you make of it,
That at the touch of a word
it will disappear.

II.

My mother closed her body to me when I was nine:
Our baths together ended
She donned at least underwear to walk the hall.
This didn't stop her from demanding
I sit open legged on a chair so she could photograph
the beginning of my pubic hair.
Shame closes on me still,
my knees touch automatically
at the memory.

I am more invaded than by any man.
The older I got
the more my mother wore in front of me

until my only image
became her fully clothed.
When i visit her now
She clutches her breast under her clothes,
fingers her waist,
she straightens her back, her hem line,
checks her make-up, smooths her hair,
does not believe my look is full of admiration,
that she is a woman aging to perfection.
She tugs at my hem lines, too,
does the kellogs' pinch with my waist,
too fat, too thin, double chin.
Does not understand why I don't bring home to her my friends.

III.

I am convalescing in my mother's home.
I have lost a portion of my breast;
I have left disease behind.
There is no question but that I am fine.
We stand in the shower, washing my hair.
She wears underwear; loose, flowing, speckled things she has
painted rooms in,
that billow with water, with wind.
I am nude but for the bandages,
knees locked firmly in place.
I will allow her no in.
But her hands lift my hair to the water like a ream of silk:
She unthreads strand by solitary strand from the mass
and offers it to the water. It is not a rinsing but a purification rite,
and all this while, her body shelters my wound from the water.
I cry out in pain, from a place where I would have to say
there has been no pain for at least
a moment now.

Lesbians Evolving Health Care: Our Lives Depend on It*

Recently the *San Francisco Chronicle* ran an article addressing the plight of the hundred women with AIDS in the Bay Area and describing the services that have been started for them, including housing, childcare, a day center, haircutting, a food bank, massage, counseling and meals.

In 1988, approximately forty thousand women were living with cancer in the San Francisco/Oakland area, at least four thousand being lesbians, about four thousand women dying. Eight thousand women were diagnosed this year. The forty thousand women don't have the services that the hundred women with AIDS have. I want the women with AIDS to have those services. I don't mean to polarize. But I also want recognition that we have a huge problem here and we need to do something about it.

According to the American Cancer Society, half a million women in the United States will be diagnosed with cancer in 1989, and a quarter million will die from the disease. Forty-two thousand women will die from breast cancer in one year, about the same number of people who have died since the inception of the AIDS epidemic in 1981. Cancer is the leading cause of death in women ages 35 to 54. Cancer has become an acceptable epidemic. As someone who has metastatic breast cancer, that is unacceptable to me.

While many lesbians continued to keep their attention primarily focused on women and women's concerns, many more women turned toward AIDS work, as shown by our numbers at this conference.

* This article is adapted and shortened from the keynote speech at the Lesbian Caregivers & the AIDS Epidemic Conference in San Francisco in January 1989; and is an edited version of the same paper published in *Out/Look* No. 5, summer, 1989, entitled "Lesbians Working on AIDS: Assessing the Impact on Health Care for Women."

Why have so many of us become AIDS caregivers? There is a clear, delineated crisis and there is a need to help people in our community. We take care of our friends who need us. Because women, even lesbians, were raised to be caregivers, we moved toward that need. We were raised to despise ourselves and belittle our needs while holding those of men to be important. Women were raised to take care of men and to serve them. My father once told me that.

And even though we are lesbians and have made conscious choices to disown that heritage, we have nonetheless incorporated many of its basic tenets. As the "other" in the lesbian and gay and women's movements, we were left out a lot, not part of the in-crowd. Working in AIDS, coming to the service of men — working in their agenda finally — served to validate our existence. It is also easier to work on something like AIDS, because, by and large, we won't get AIDS, nor will our lovers or our lesbian neighbors. And AIDS is something the whole society is addressing; we can actually fit in, we can be considered heroic and important and decent and be recognized for it. We can even, sometimes, work in a queer environment. We get to work where our hearts lie. The work structures are set out for us; the funding is available.

This is not to say that working on AIDS is easy or that we don't care for and love the people we know with AIDS. It is to say that we make excruciating choices without even being aware of them.

Lesbians were and still are in the vanguard of the women's and lesbian and gay liberation movements. Without us, there would be no rape crisis centers, no women's foundations or buildings, no awareness of domestic violence, no women's music festivals or women's radio programming. There would be no National March on Washington, AIDS quilts, AIDS food bank or many other AIDS services, especially those for women. Without us, the women's movement would not have addressed homophobia and heterosexism and the lesbian/gay movement would not have addressed sexism. Indeed, without us, these movements would have remained one-dimensional reform movements. With us, they become dynamic forces for social change.

What has happened to the women's movement and community since the AIDS crisis started? While it still pulses with

creativity and excitement, many institutions, organizations, services and political agendas have been slowed or disappeared. Not just because of AIDS, but because of general disinterest. Here in the Bay Area, there is no more *Plexus*, A Woman's Place Bookstore, Berkeley Women's Center, San Francisco Women's Health Center or Lilith Theater group, to name just a few.

Right-wing groups like Operation Rescue are harassing women at abortion and birth control clinics and bombing those clinics. Why aren't we marching in large numbers to protest? Violence against women is proliferating at enormous rates; we're murdered, raped and beaten every few seconds, yet few people decry violence against women. Why don't we make it clear that there is a hate campaign targeting women and that it is not new? Why aren't we screaming that sexism kills?

No one takes care of women or lesbians except women or lesbians, and we have a hard time taking care of ourselves, of finding ourselves worthy and important enough to pay attention to. Why doesn't the lesbian and gay community mobilize around the urgent needs of women and lesbians? Why don't we even consider our needs urgent?

As a woman with cancer, I have learned about how serious our needs are, about what we need and what we don't have. As Lesbian/Gay Liaison to the San Francisco Human Rights Commission, I found myself waiting for my first biopsy results in May of 1985 at a Lesbian/Gay Advisory Committee meeting. Our meeting focused on AIDS and I remember thinking, screaming internally really, "What about me?" Well, I quickly found out what about me.

I felt invisible in our community. I had a lumpectomy followed by radiation, survived, and was expected to go back to work—to work on AIDS—and life. There was little recognition of what a woman with cancer goes through. What I found was a community willing to address AIDS, but no more. I found that the things that were offered for people with AIDS did not exist for people with life-threatening illnesses; that some of the problems that existed for people with AIDS existed for all people with life-threatening illnesses, and yet our community, and society in general, has been one-dimensional in its approach.

If you have AIDS in San Francisco, you can go to the AIDS Foundation for food and social services advocacy, get emergency funding through the AIDS Emergency Fund, and get excellent meals through Project Open Hand. Your pets are taken care of if you should land in the hospital or if you're too sick to take care of them. There are clinics and alternative centers and organizations fighting for drugs, research and mental health.

If you have cancer, you wait endlessly for a support group, which if you are a lesbian, a woman of color, working class, or believe in alternatives, you don't fit into anyway. No organization shepherds you through the social service maze, no organization brings you luscious meals or sends support people to clean your house or hold your hand. No organization fights for your needs, no one advocates for you.

I'm not saying this just to pick on our community. We live in a society that, by and large, does not take care of its sick. In the case of AIDS, we have built a model as a community. This model does not exist outside of AIDS. This model was built by lesbians and gay men to serve people with AIDS, but it does not serve our entire community.

Cancer, like AIDS, is about living, it's about living with a life-threatening disease, in whatever stage, whatever condition. Although each of us experiences cancer individually, it is through collective support and action that changes take place. As an activist, I always believed that, and my own cancer experience strengthened that belief even more.

Organizing is needed for all diseases. All disease and illness in this country is political, not just AIDS. For myself, I learned to make a will, a durable power of attorney, to have someone at doctor's visits, to tape-record those visits, to build support.

And I took some of what I learned doing AIDS work and a lot of what I learned from feminist organizing and women's liberation, and with other women, created the Women's Cancer Resource Center. We desperately needed a resource, support and advocacy center where women with cancer could be empowered to make their own choices and be supported by other women in their situation, a center controlled by women with cancer.

The Women's Cancer Resource Center has been slow to grow, partly because some of us had or have cancer and need to take

care of our health. Additionally, a lot of energy is going into AIDS from the women's community, and there is little left over for cancer or other disease and disabilities. Regardless of AIDS, women have reduced their organizing work and settled into solely working on themselves instead.

Although we are an agency that serves all women with cancer, we are not in the closet about having lesbians on the advisory committee or serving lesbians. Consequently, we receive little funding due to homophobia. Funding agencies think they are funding the gay community through AIDS. Women's groups controlled by women and for women get little funding by foundations, businesses, people with money, gay men, or other women. Women's agencies are not so popular, women's issues get pushed aside.

Despite all those obstacles, the Women's Cancer Resource Center thrives. We've just gotten our own space. The advisory committee works on funding and programming, we have support groups, we do forums and educationals, and information and referral and counseling.

When I found another lump in the same breast, I went for further tests and discovered that the cancer had spread to my lungs and bones. I could not believe that I was so ill. I had been exercising, feeling great, working long hours, just like the first time. I knew the implications; I knew women who had died of metastatic breast cancer. Yet, the reality is also one of survival — and for a good and productive life. It is now over a year later. In my first round with cancer, I was always making decisions that had to do with my survival; this time, I agonized over every decision as my life lay fragily before me.

I made my decisions with what I had learned as a cancer and AIDS activist, as a feminist. I went through my treatments, I did my research, and live with a great deal of support from my lover Teya and my friends and acquaintances. With the first diagnosis, my life's axis permanently tilted; with this diagnosis, I live constantly on the edge.

From this vantage point, there are certain things I want you to know, to take with you, to think about, to change.

The most important thing I want you to know is that lesbians

do not have a support network. Disabled women have found it ironic that this conference is addressing lesbian caregivers in relation to the AIDS service community, but not the women's community. One woman told me that although about 80 percent of the disability attendants used to be lesbians, there are only a handful left.

Support and caregiving in the lesbian community often becomes a matter of personality. There are so many women with health problems, be they cancer, environmental illness, chronic immune deficiency syndrome (Epstein Barr), multiple sclerosis — but no one recognizes that these are serious illnesses, and that they need to be taken care of. Indeed, because they are women, the community has not mobilized.

Just as we were healers, experts in our fields in the Middle Ages, we need to lay claim to our heritage now. We have many people in nascent stages of expertise, but few experts. When we started the women's health movement, we were taking control of our bodies, mostly in the areas of reproductive and gynecological health care. Now we need experts in cancer, lupus, arthritis, environmental illness. I mean practitioners in allopathic medicine, Chinese medicine, or homeopathy. Going to a doctor, hoping for non-homophobia, is not enough. We need practitioners and clinics that are supportive of us as lesbians and experts in their fields.

When lesbians get sick, they also get poor. Women are on the lower rung of the financial ladder, and when they become ill, the bottom falls out much quicker because they are closer to it. They lose their health insurance and can't get any anymore. If they are lucky enough to have a job, they have to stay in it. Many women I know work when the act of working is almost physically unbearable because they can't afford anything else. Some women would love to work but no one will hire them. Some women are on SSI but hardly making it since, cruelly, the amount is so low.

AIDS is a new disease and fresh in terms of who controls information about it. Information and resources about cancer, however, historically have been controlled by the American Cancer Society. Its board, as well as those of other cancer institutions, is composed of people with a lot of power to keep things as they are: chemical company executives, the Rockefellers, the very

scientists standing to get money. Research is geared towards big bucks, not to actual prevention.

Actual prevention would mean changing society — cleaning it up — and that won't happen. When they say prevention, they quite often are talking about small individual prevention like quitting smoking and cutting fat consumption, or early detection, like mammograms or self-breast exams. When they find a tumor in your breast in a mammogram, you already have cancer. They don't mean going after the tobacco industry; they don't mean stopping pollution or providing quality food.

We need a National Cancer Institute that does relevant research — not research into a quick cure that costs a fortune, but into real prevention, into real cure. Everyone knows pollution causes cancer, but does NCI or the American Cancer Society do anything about it?

That's where AIDS can make some inroads. Just like we question what is said about AIDS, we need to question what is said about cancer or chronic fatigue immune deficiency, or any other disease. We need to question current concepts of disease.

There are a few things going on in society, in which our community participates, that I find particularly obnoxious. Over the last several years, the women's movement has become co-opted by professionalism. This has also happened in the world around us. Our society has taken the individual who may have known something and rendered that person useless, so that she has to turn toward experts to tell her what to do. What they usually tell her is individualizing and internalizing.

Earlier in the women's movement we took what victimized us — rape, battery, incest — and worked toward changing society, while making ourselves stronger. Now we work on ourselves individually. Most of the work is therapy work. Without changing the environment which allows such victimization to take place it is allowed to continue. In that vein, there is a new disease model which holds the individual responsible for her illness. I call it dumping. I call it psychobabble.

With it has come a lot of new-age jargon about the fitness of self. We are a culture obsessed with what the individual can do to look good and stay healthy — we can jog, exercise, eat oat bran, stop smoking. This is not to say that people cannot affect their

own health. But this form of thinking says that it is all in our power. So if we don't stay healthy, we must have done something, or worse yet, if she doesn't stay healthy, she must have done something. It doesn't change a thing; it internalizes illness and blames the victim.

This form of thinking plays out the concept that we create our own reality, that we have ultimate freedom of choice and total control. Fuck the world around us, the people around us, the government and corporations, even our own biology. They don't exist. They don't affect us. There are no such things as sexism, homophobia, racism, anti-Semitism, capitalism, pollution, biology.

I cannot begin to tell you the number of people who believe and have said that I must not have had a positive attitude, or I wouldn't have gotten cancer. This is cruel. Also, don't get angry, anger is bad. I have heard that I worked too hard, that if I had just concentrated on myself I wouldn't have gotten sick. Don't do anything meaningful. This thinking comes from a society that doesn't want us to be angry, that doesn't want us to be activists.

Some people say having cancer is a gift. Having a life-threatening illness is not a gift. You wouldn't want me to give you cancer and I don't want it either. Yes, my life has changed, and yes, I have learned from the experience. But I don't have cancer because I have something to learn from it. I have cancer because the cells in my body malfunctioned.

Cancer is said to be an emotionally caused disease because the scientists don't have a cure for it and they are not sure how it is caused. If we keep it on an individual level, we need never find that cause or the cure. Before they found a cure for tuberculosis, TB was thought to be emotionally based. There was a TB personality just like there is a cancer personality, and people tried to visualize away their illness. As Susan Sontag described in *Illness as Metaphor*, once a cure was found for TB, all that was tossed out.

The other dangerous thing we have in our community is the idea that not only do emotions cause cancer, spirituality does too. Somehow something we have done in the past is causing our troubles now; we are working out our karma, what goes around comes around. I guess that's why women are raped and Black people are lynched — it's karma. Take the onus off the perpetra-

tor. Accept the unacceptable. Forgive the unforgivable.

Somehow a community founded on feminist principles, a community founded to change society and its structures to those that are life affirming, has taken on the individualist ideals of capitalism. By doing this, we unthinkingly tossed out the notion that we are impacted by our society and our deeds affect that society. Until we understand that our actions are meaningful, we will work individually and change will not occur.

I think this has happened partly because it is easier to deal with disease, or any wrong, really, on an individual basis. That way we can believe it won't happen to us and maintain the illusion that we have control in a society out of control.

We live in a world with acid rain, with a hole in the ozone layer, where food is mass produced and picked early with no nutrients, where pesticides are sprayed on the workers and the food we eat, where the animals we eat are raised in a tortured environment and fed hormones and antibiotics; we live in a world that has chemical dumps under housing tracts, schools, playgrounds, with nuclear weapons and dumps, where winds spread radiation over all of us. This is labelled pollution when, in fact, it is invisible violence.

Our country has no national health care system. Society turns away from the homeless. Chemical company executives sit on the boards of the largest cancer organizations and control what kind of research is done. Society must change and redirect itself to be life affirming; where individual welfare and health care is respected; where profits don't count more than people; where we are free of chemical and radiation hazards; where good, healthy food is available; where each person is known to be significant and worthy of life.

Let's see ourselves as healers, as workers. We need to make connections and engage in critical thinking, to see the universality and interconnectedness of issues. We need to take the skills we have learned as feminists and apply them to our work on AIDS and to our work with women. And then take the skills we have from working with AIDS and apply them to working in women's health care. Let's bring it back home.

As individuals in partnership with others, we have to be working on women's health issues. We can strongly protest a

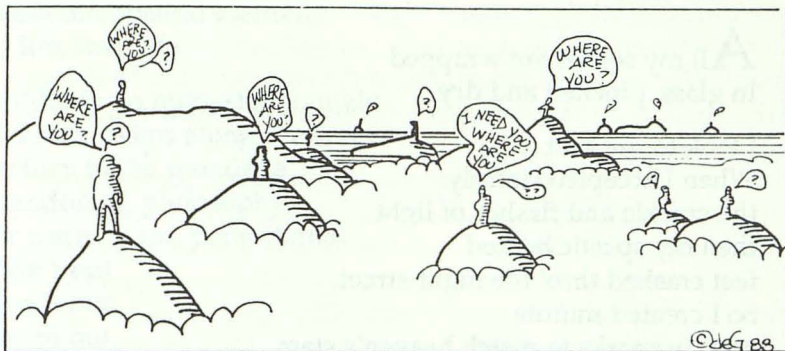
Department of Public Health for not funding women-specific health care. We can be out there in huge numbers protecting reproductive health and fighting the Operation Rescue people. We can build a lesbian-health support network, so that lesbians who need help are brought meals, taken to appointments and so on. We can support institutions like the Women's Cancer Resource Center* financially and through our skills. We can do this and more. We need to be screaming in the streets that we will not be killed by the dissolution of the earth and make the government accountable to the people.

I have wondered whether the urgency I feel comes because I have cancer, but I think that it only has brought it closer to me. I firmly believe that we are on the brink and that we must be very forceful in order to stop the destruction before there is no us. We have to stop being nice girls, and start fighting as if our lives depend on it because they do.

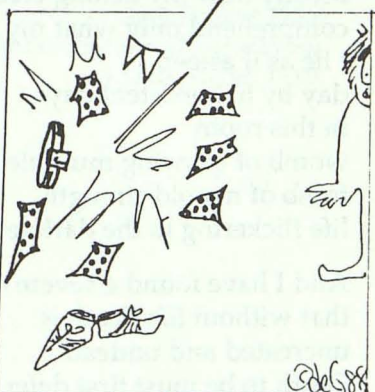
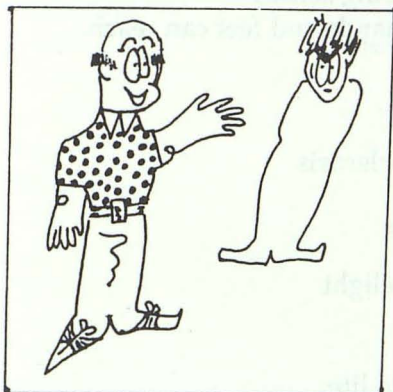
Special acknowledgment and thanks to my lover Teya Schaffer.

* To receive information about, or make a donation to, the Women's Cancer Resource Center, write PO Box 11235, Oakland, CA 94611, or call 415-548-WCRC. Make checks payable to the San Francisco Women's Centers, Inc.

from *Some Days I Have Cancer*
More Than Other Days
A Cartoon Journal by Pam de Gaines



SOME DAYS I HAVE
CANCER MORE THAN
OTHER DAYS.



HELL, CHEER UP! WE ALL HAFTA' GO SOMETIME! WHY, YOU COULD
BE HIT BY LIGHTNING TOMORROW.!

Pam de Gaines
September 23, 1939 — August 24, 1989

Mandy Dee

Night

All my senses are wrapped
In glass, pinched and dry

I look to my past
When I accepted fiercely
the crackle and flashes of light
then my spastic booted
feet crashed thro' the night-street.
So I created minute
earthly sparks to match heaven's stars
and I loved my small striding;
resounding my presence to others —
the quiet walkers
and bland straight standers.

Mostly now my itching creeping senses
comprehend only what my hands and feet can reach.
I lie as if asleep
day by half existent day
in this room
womb of growing multiple sclerosis
tomb of my old strength
life flickering in the darkness.

And I have found a severe delight
that without life death is
uncreated and undead
Death to be must first defer to life.

If the universe and mine utterly disintegrate
and unbecome
death must disperse into chaos
and the root of all creation cease.

So though restrained within one room
and my flashes of defiance
are now restless sclerotic jabs
and hardly painless;
I proclaim
death interspaced eternally
by life, then life

Suddenly no more stars tonight
Sickness creeps along my spine
I return to the mundane
abandoning philosophy
for warmth and paracetamol
breath out
breath out
breath out.

16th October 1985.

*Mandy Dee died of multiple sclerosis
on 31st October, 1988.*

Adrienne Lauby

This Mirror's Not In a Bar

Vonda owns a sailboat and used to be a lawyer. She's new. Her check-in at Disability Group always sounds like a doctor's report. We all talk about what happened to us in the past week and Vonda tells what medical tests she had. She never asks for time beyond check-in but she often explodes in the middle of someone else's time. I'm afraid of her. I'm always most afraid of the new women, before I get to know them. Every week I think they will die unless I do something to help. That's my arrogance and how I want things to be exactly one thing or another, the part of me who thinks death is better than uncertainty.

Vonda doesn't believe she has to talk about her emotions. She thinks she has them under control. By now, her fourth week, the rest of us know different. But we try to be patient when she interrupts us. Like Mil's crack, "Since we're all patients, the least we can do is be patient with each other."

Today Vonda said her liver functions were worse and my fear slides from its hole at the base of my spine like a rattlesnake from its hole. It struck for my guts. A doctor told Vonda to stop the blood pressure pills but last time she did, she said, she fainted driving down a suburban street. The rattlesnake twines through my ribs. Vonda doesn't like to eat. Mostly she doesn't, except the doctor told her to try to remember. Now that snake's got its tongue out, tasting the breeze near my heart. (That's hard because my heart is my weakest organ.) Vonda says it would be okay if women from the group call her some time but they shouldn't expect her to say anything back. What is she trying to tell us? The snake rises through my forehead and stands up from the back of my skull. It enters the room, gazing at these women I've come to know so well. Except Vonda. Vonda's new and makes no sense to me.

What am I afraid of? I'm afraid of what I am: sick, poor, sexually alone. And what does that have to do with Vonda? She's my mirror and I can't stand to look.

I can sit and feel the fear. I can force myself to let the rattlesnake curl. I can stop myself before I try to take care of Vonda. I can remind myself of when I tried to take care of Liz, Pat, Juniper and Mil, each time only proving I could barely take care of myself. I can come to this room every week and look at my fear, listen as Vonda gives her medical report.

When my able-bodied friends ask me about the group, I tell them something rational. I tell them about the neurologist who refused to treat Mil until she lost twenty pounds. I tell them about Liz's parents coming to visit.

Liz's father retired from a county road building crew and drove out with her Mom to see her. He watched for a day and then started touching her arm for curbs and walking half a step behind to let her set the pace. Neither he nor her Mom complained or seemed impatient. It made her notice how often her middle class (younger) friends give her a hard time that way. But when she tried to talk to her parents, they changed the subject. "I counted," she said, "The farthest I got on any disability topic was two sentences." Her guess is they didn't want to hear the word "blind."

Telling someone that story is very different than sitting, sweating, as Vonda talks. Vonda says next week she's going to an endocrinologist. I'm not sure what that is but it feels like a sixty-mile-an-hour rattlesnake strike.

Yesterday afternoon I cried instead of taking my nap. I do that often. Yesterday I cried because I do it so often, because lately I've spent too much time in bed, alone, waiting, crying instead of resting my heart. I've never talked about sex in group before but yesterday as I wailed, knowing it would leave me too tired to make supper, I promised to do it this time. So, after everyone had a chance to check in, I said I want some time to talk. The other people in this group often tell me I'm brave. Today I believe them.

In a smaller town these women would already know some of what I have to say, how it looked like Jan and I had a great relationship but she left me for Kate. Maybe they'd guess the other part too, that our sex was routine and Kate clearly offered something better. How, ever since, I've been in the beggar role. I say, "Francis," and the old timers in the group look at each other. They do know about Francis. Probably they've guessed that it

was the bedroom which held me to Francis. They must have known there was something as, week after week, I told stories of how she teased and humiliated me in every other way.

By the time I broke up with Francis I'd burnt off ten hard-gained pounds in stress and self hate. It was nine months before I got my meds balanced enough to leave the house more than once a week. Now I say outloud how sometimes I think it was worth it. The thing about Francis was Francis demanded I show her what I wanted in sex. Francis said it was my job to show her what I wanted and I should figure out how to do it with my body because she was bored with talking.

"You want to have fun?" she said. "I'm here. Start moving and rubbing. Just don't expect me to do the work for you."

I was hurt but I tried — and could not believe what it touched off in me. Two women in a bed, each trying to get what she wanted — we started fires to burn down cities. I needed my pounds for survival. I had to leave Francis. But I wanted to stay and dance naked with her in the bonfire. I wanted to find my own matches, learn enough about flames to look back on our raging heat and see it in perspective, as contained as a candle. I still yearn, flame up unsatisfied, cremate my naps.

By the time I said this much I felt awkward, all wrinkles and flesh, big feet and stubby hands. I'm sure these other lesbians learned this stuff in their twenties and, if they didn't, they're not about to tell me any different. But I didn't stop. I need to start sleeping during my afternoons instead of listening to a snake hiss loss at me from between my legs.

I cried. I whined. I drew pictures of twenty more years of sleeping alone. I complained I could die next month before I have even one more chance for love. I carted out words from my nightmares, "lonely... cold... unwanted... bitter..." Accompanied each one by another gush of tears.

When I finished people said some empathetic, encouraging, sympathetic sentences and I had time to mop up the puddle I'd become. I was about to nod for Juniper's turn when Vonda started in.

"The worst part of the hospital this time was the day a resident came in to talk about AIDS and safe sex."

Her voice was slower than usual, but it seemed lower too.

Maybe I'm wrong. Usually she blurts her interruptions out with anger at someone who isn't here. This time I thought she was having a conversation and maybe it was with me.

"He asked my sexual orientation and the frequency of my sexual contacts. I barely got the words out to answer. I could only think, 'I'll never have sex again!'"

She looked at me and for the first time I noticed how thin her hair is around her face.

"It could be true, you know."

That's all she said.

Maybe Vonda's afraid of dying even more than I am. They say sexuality is very connected with fear of death. I don't know. Maybe she will die and I'll be alive. Or maybe it will be me first. Maybe one or the other of us will find a lover sometime. Maybe we both will. I don't know. But I feel she's given me a gift and I believe I gave one to her.

After that I don't remember much about the meeting except afterwards when I walked outside to squat beside Mil until the van came. We've made this our friendship ritual in the past month. Today she told me I was brave and I'd made her think.

"Who knows? Someday I might lose Aggie and have to go through it all again," she said. "Last time I was single I was able-bodied. Where would I find a lover now? Should I look for someone using a chair or someone who likes to play poker? I can't imagine finding both."

I've always liked Mil. She's got an admirable one-two-three kind of practicality combined with this slashing sarcastic wit.

"If it ever comes to that," I said (bravely, joyfully), looking past her curly gray hair to stare in her deep brown eyes, "Call me up and ask what's going on with me."

"I guess I could give you a hug in the meantime," she said.

So I let my arms find their natural niche in the sun-warmed width of her shoulders.

"You better be careful," I purr. "You don't know what you're getting into."

She pulled on her leather gloves to wheel to the curb cut, looked over her shoulder at me and said, "Hot!"

I Want To Love You Hot

For Frieda

I want to love you hot
my heat rising
deep burning passion
sparks fireworks
sizzling desire
but when I lay in bed
day after day
unable to fix myself food
wash dishes
or even bathe
there's not much left
for even thinking
of hot sex.

I want to love you hot
hour after hour
of non-stop sex
in the afternoon
at the beach
in the back of my new car
but when my breath
won't take me up the stairs
wakes me from dreams
reaching desperate
for my oxygen
there's not much left
for hour after hour
of hot sex.

I want to love you hot
pleasure you
with new positions

watch your head turn
as you moan
to the rhythm
of my skilled fingers
but with lightning
streaking through my limbs
the forever aching
in my muscles
there's not much left
for gymnastics in bed.

Lover sweet lover
I do want to love you hot.



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Sandra Lambert

from Disability and Violence

...I remember that all oppression is maintained by the very real threat of death. The more successful the oppression, meaning the more it is considered normal or regular or "the truth," the less this tool of violence is needed. While violence continues to be firmly embedded in the system, it is camouflaged.

Physical violence is perpetrated on disabled people in many settings; from the isolation of the nuclear family, to the daily, almost routine physical abuse of institutional care. An extremely successful disguising of violence is when it masquerades as "medical care." We call them hospital rooms, not torture chambers; examinations, not violations; treatment, not abuse. A history of childhood hospitalizations and surgery provides my own primary experience of physical violence. Other than a few first person accounts, there is little written that addresses my life....

The search for my childhood has in large part been the stripping away of the camouflage and renaming that surrounds this type of violence. I read my hospital chart from when I was a baby, "The splint was not tolerated." This means I was in such pain they were eventually forced to remove it...I lived in a world where loving parents inexplicably and repeatedly abandoned me. The strangers they left me with hurt me. No matter how obedient and good I was, or how much I begged, or how hard I fought, they still hurt me. There was no sense of outrage. It was all considered normal and for my own good, and I was supposedly very lucky to get the "care" I did. I do not think that my experience is unique.

This stripping away of the lies of the past gives me clarity about the present. One piece of clarity is a realization of how much I pretend to forget. I pretend to forget how deeply disabled people are hated. I pretend to forget how this is true even within my chosen home, the lesbian and feminist communities. My survival at every level depends on maintaining good relationships with able-bodied people. Pretending can make this easier.

Where Have All the Lesbians Gone?

As a disabled woman, it especially bothers me that there is no distinction made between dealing with addictive behavior and dealing with someone who has needs because of disability or illness. It has become almost "politically incorrect" to choose to work for, or even worse, become lovers with, a disabled or chronically ill woman.

Since I moved to the Bay Area in 1978 the lesbian community has gone through some radical changes. Some of these, such as increased awareness of the amount of alcoholism within our community, have been positive. I view change as positive when it empowers the community and individual women. Other changes have not been so good. The concept in Alanon that you are never really healed is one that disempowers women. This may work fine with recovering alcoholics, where one drink can lead to devastating consequences. It does not work when discussing a learned behavior of co-ing. The idea that one can never have healthy relationships without the help of Alanon is taking a lot of power away from women. The move towards Alanon in this community is frightening to me.

One of the most destructive concepts to the lesbian community is the lack of clarification between caring for someone and co-ing. This is a contributing factor to why we are running short on lesbians in the helping professions. I've especially noticed the effect of this on the disabled community and chronically ill women, such as those with cancer.

The number of women affected by cancer is growing every day. We have our own health crisis right here in the lesbian community, yet most of the community's energy is going either to self-improvement programs or to gay men with AIDS. Attendant care for the disabled is in crisis because there are so few people willing to do the work. It's not in style to be an attendant anymore. When I was an attendant, the majority of attendants were lesbians. It seems like a vast number of women are learning how not to let the problems of others affect their lives.

There is a basic difference between caring and co-ing. Caring happens from the heart, where the act of giving to someone else enriches your life and makes you feel good about it. The words "co" and "co-ing" have become integral words in lesbian language, yet few seem to understand their true meanings. Co-ing comes from feeling that it is your responsibility/duty to do something whether you want to do it or not. It leaves the woman who does the giving feeling resentful for having given so much and getting so little back. In the true Alanon sense, co-ing situations come up when someone is not clean and sober. So, much of what you do for that person isn't even remembered, never-the-less appreciated by her.

Co-ing can also happen without the presence of substance or alcohol abuse because some women have learned behavioral patterns of feeling like they have to take care of everyone and everything, making everything nice, and other women have never learned how to give, they only know how to take. But these patterns can change. Women can re-discover, or discover for the first time, what it means to care, rather than "co."

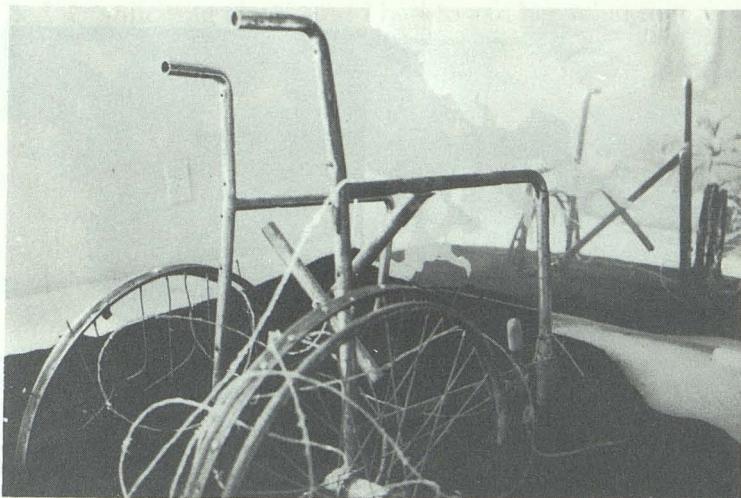
True caring involves an exchange of energy. When a friend is in need, and you help them out, it makes you feel good just for the joy you bring to them. In friendships this energy flow is very back and forth. When you need a hand, you can count on a friend from a caring relationship to be there. At its best, this is a very equal exchange, not necessarily in the exact amount or type of energy, but in the love shared. As an example, you might help a disabled friend paint her room. While she probably won't be able to do this for you, she may be the one friend who shares something special with you, such as a loving wisdom.

As a disabled woman, I am a writer, counselor, resource-person, thinker, sometimes a great lover, and a good friend. I require physical care for survival as do many disabled women, and I give as much as I've got to those around me. To care about someone who's disabled isn't a one-way street in a healthy relationship.

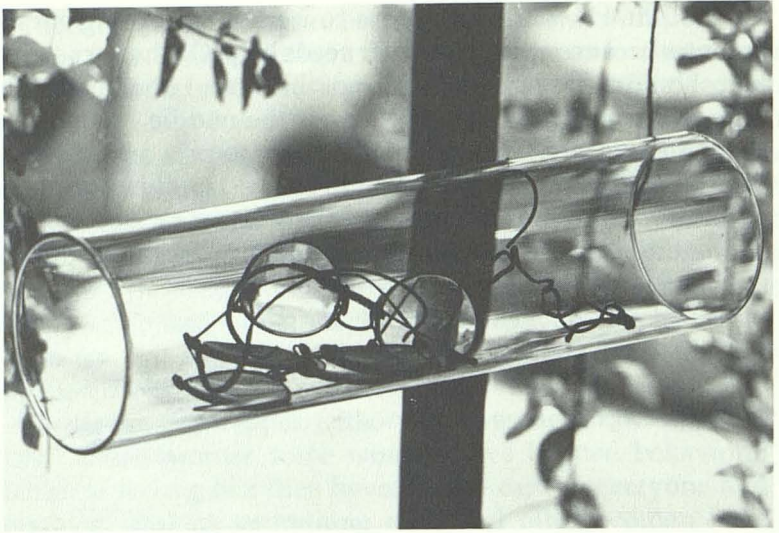
There is a difference between alcoholism and disability. A disabled woman has no way of changing the course of her disability. No matter how much she takes care of herself, the disability can put her in a position of needing help.

It shouldn't be a crime to skip a concert or miss going out to the movies because a friend or lover needs help. On the very same line, it shouldn't be a crime to say, not this time, I don't have the energy, when that's the truth. Where is the middle ground we need so desperately? It's equally important to take care of one's self and needs as it is to be willing to help each other out. As a community, we need to continuously care about each other and examine the ethics with which we guide our lives. No time is better than now.

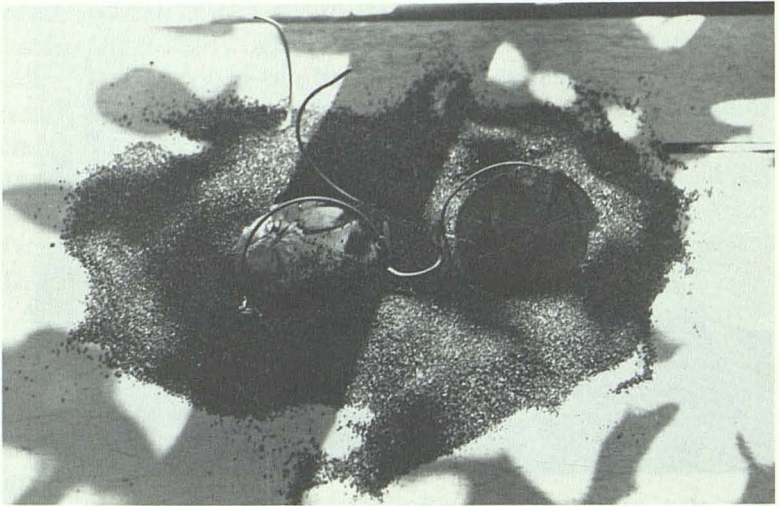
© 1989 Diane Hugs



Wheelchair Access
Sculpture by Alison Ulman
Photo by K.S. Duffy



A Moment of Doubt



Sweet Denial

Sculptures by Alison Ulman

Photos by Julie Potratz

from What's It Like to be Blind?

(And please keep all that other stuff quiet.

We can only deal with one minority at a time.)

Yah, we do what we can
in between jobs,
you blind?
Then that's most of the time.
When a friend gets hurt
you blind?
then that's too often.
In spare moments when we feel like it
and WHEN WE HAVE NO CHOICE.

... "What's it like to be blind?" What shall I say? Shall I tell you how it felt the first time a welfare worker asked me if I beg? She called it "soliciting alms" and I had to ask her what that meant. She's not required to ask anyone else, just us. ...

Shall I tell you how it feels to be accosted on the street by religiously ill people with a point to prove? (I must have sinned, don't have enough faith, need THEM to pray for me. One told me to stand still so he could spit to make mud to place on my eyes like in the Bible.) Or sick men who want to tell me about the last time they abused a blind "Girl?" "Oh, you wouldn't even know who raped you."

Do you want to know about job interviews where it was thought amazing I could dress appropriately and arrive on time, or where my dog guide was the subject discussed? (Another interview screwed.) I can't eat being amazing, I can't keep warm with it or pay bills with it or even use it to wipe my ass. ...

Why don't you know about our struggles with the airlines, schools, colleges, potential employers, getting admitted to restaurants and movies with guide dogs, finding landlords who will rent to us, and "rehabilitation," "welfare," and government agencies who have the power to affect every aspect of our lives?

Why aren't there self-defense classes taught by women for disabled women?...

I call the fire department because of a hot plug in a receptacle. The firehouse dispatcher is a friend who knows I'm blind. He says it on the radio and a stranger hears my address and disability on his police scanner. He arrives to save the day and stays, breathing alcohol into my face and trying to get close after the firemen leave.

A woman publicly praises the mother who abused me for doing such a wonderful job. The reason it's wonderful is that I'm blind and it must take a special kind of person to raise a blind child....

Why must I always fit myself into others' categories so they can have me, neat and tidy, in square boxes? Why can't we all work at becoming spiritually big enough to understand something of all that each person is?

The good reverend at our blind people's meeting makes some joke about a lady who's "deaf as a post." ... Somebody makes a queer joke in conversation after the meeting.

"This is the fifth floor," the man says in the elevator at work. "And your stop's six, that's next." He doesn't say it to sighted workers and I've worked here two years.

Once a blind man asked me, knowing I'm Cherokee as well as white, "You know how you can tell when an Indian's having her period?" I told him I didn't want to hear it.

Lesbian friends say it's bad when men who are disabled or of color get shafted but I have to remember that because they are men they have the power to shaft disabled womyn and womyn of color....

YOU ALL try to cut me into little pieces, keeping for yourselves only those bit to which you best relate. ... I live alone, in silence, away from question-barbs. I reach for the sky, walking outside to lift my head to the encompassing sky, full of airs and stars, and room enough to be.

Hallowmas Circle Trapped Inside My Body

She's sitting between my legs but I don't feel her. I'm in trouble. I send her for help. I'm fading. My mind says maybe they will leave soon and I can fake my way through this. My mind is moving so fast but my body continues to fade. There is a womyn to my right — she's trying to hold me up. Oh! There are many womyn pulling me on the floor into another room. What a way to end a wonderful week-end — trapped inside my body.

Where am I — Where is Lori — What about Katy?? Oh, I'm at Pagoda.* New womyn look at me. I sign "fast fast toilet." I hear talk, plans on what to do. I try to hold that muscle while they talk and plan. I'm not even sure that that muscle is there. "Too late" I sign. I'm trapped inside my body.

My back is hurting. Like being on an operating table. I write saying "no hospital." She looks at me and says "no hospital." I believe her. My head is exploding. My right side is numb. — Yes, I hear you, Kay. — I wish I could talk and repeat all that I hear. I try to sign. — Damn! — I think I should learn more sign. She's singing to me now. I smile. Oh, look there is my body on the floor. I'm in the sky. Loving womyn around my body. Maybe I'm gonna die. Maybe the hospital. I'm back — trapped inside my body.

I want to go home. I'm confused. Oh shit! I'm now at the top of the stairs. My body feels like 800 pounds. "I want home!" I don't care if I fall down those stairs. I don't feel anything anyway. I see Val at the bottom. She looks very scared. I'm a strong dyke even in my weakness. Oh thank-you Goddess — I'm in my wheel chair — I'm going home. Trapped inside my body. Trapped inside my confused mind.

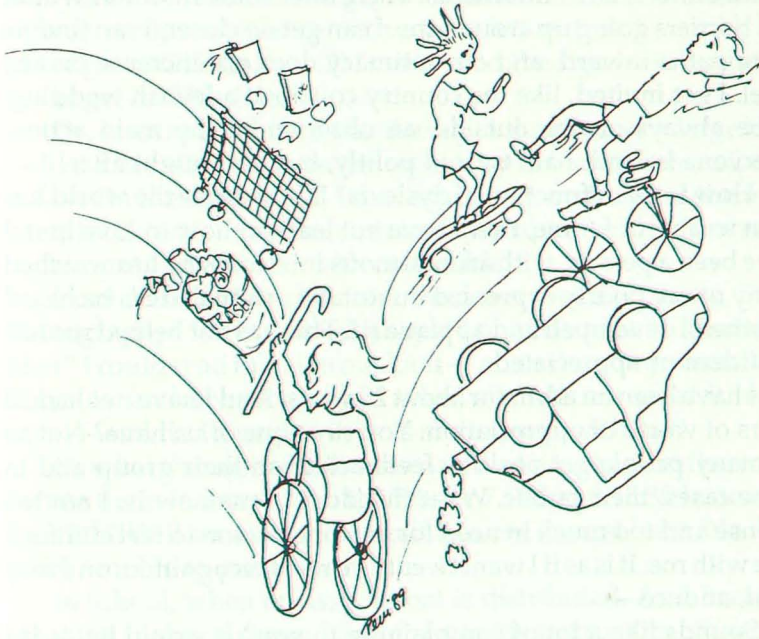
This originally appeared in *Hikané, the disabled wimmin's newsletter*, #1.

*Pagoda is an ocean-side lesbian residential/resort community.

Fever

hot sparks shoot thru rivers of pain rain
blood splatter everywhere what happened to you?
melted globs of metal stuck in your side
piercing your skin thru layers layers you didn't
know you had so many layers fever girl
it all started with fever hot breath on cold
winter's nite shivering shaking with the
cold then the heat body twisting in a dance
you had no control over fever girl 'til
you thought you would die had seen your
death in the eyes of the woman standing
over you holding the cool cloth to your
heated brow fever girl 'til it
dropped and you thought you were prisoner
in an Aleutian Island ice cave stuck
with the shivering you couldn't stop
the shaking the cold biting to your bones
hurting they put you on morphine to
forget the pain spasms shooting down
your spine new stitches on your spine
feeling like it would burst open with
all the pain you held inside you
the morphine put you on a comfortable
cloud soft cushy you didn't want to
come back down why come back down?
your body hit the hospital bed with
a thud and you spent months trying
to put together the broken pieces
of your mind fever girl it took
you to a place you never quite came
back from it took somethin' out of you
too scary to one more time feel your

death move thru you one more time
to think it's over and you been wantin'
to live tryin' to live so bad so
hard fever girl come back home
i'm waitin' for you with a soft
bed and lovin' arms.



Crip Fantasy #2
Peni Hall

Dyslexic Dispar

The trouble with crying while driving is that one's vision can be blurred.

My life is always a little blurred — Peoples speech blurs, slurs, I loose words — and find people shouting at me, often angry if I can't get what they say the first or second time. I'm not deaf — or severely hearing impaired, — I'm dyslectic.

I know that it is annoying to be with me — but I never really realized how much until I began to ask friends what the barrier was between us.

Friendship, for me, would start out fine — we'd speak — find mutual interests, mutual ideas. Then, after some months I would feel barriers going up around me. I can get no closer, I can find no more paths inward, and our intimacy does not increase on any level. I get invited, like the country cousin at a Jewish wedding, to be always on the outside, an observer of the main action. Everyone is kind, I am treated politely, but not sought after.

How is this a function of dyslexia? It is because the world has been so absent for me, that I have not learned how to Live in it. I have been a person, with an enormous intellect, who has watched many of my poorly expressed but totally original ideas be heard by others, developed and applauded. This has not helped me feel confident or appreciated.

I have been an adult for about 20 years, And I have not had 20 years of worth of appreciation. You say none of us have? Not so — many people get positive feedback from their group and in some cases, their public. What this does to me now is: I am too intense and too much in need for any one person to feel comfortable with me. It is as if I want twenty years of recognition, on every level, at once —

Sounds like a lot of complaining to you? It would be — if I could change myself. But being dyslexic is not like being alcoholic. It is not a disease, and it can't be cured. I cannot change my behavior without positive reinforcement. And I can't accept, any more than any one else can, words that are said for their effect.

Words of praise can be brief, and scanty but they must be from the heart.

What else happens because I'm dyslexic? Well, in the writing group, after we read a piece of writing that someone has given us copies of, we go back over it. I can't ever find the place, therefore I can't follow the criticism, and slowly I stop trying. I can't find my voice, don't know what to say, am lost and divided from my group. The voices around me blur — I am fuzzed out. I feel stupid, stupified, of no value. There is no way that positive energy is going to come to me in this situation, no way that I will be helped to change.

What other things happen?— There are the simple physical things — like I'm driving the Freeway, and the sign says — Glendale right, Burbank left. I want to go to Glendale. There are 3 possibilities — (1) I could read the sign the same way that everyone else reads it, and get to Glendale — (2) I could read the sign correctly and mix up which road is left and which is right, and never get to Glendale — (3) I could read the sign incorrectly and never get to Glendale.

Or, I can spend hours wandering in the maze of a large Bldg — like a hospital, because the room map is incomprehensible to me —. On the other hand, I could instantly understand the most complex directions and mountain road maps — and get from one back county to the next with no trouble.

I can look at the signs on windows and see "Long Term Photography" when indeed it says "Lonny Tunner — Photographer" I could read this sign out loud — and ask a companion what it means, and be embarrassed when she tells me what it really says — and do I imagine it, or is she annoyed with me?

Or what if someone tells me a date and time to meet them and I write them inversed, like the 7th for 7 PM and 12:30 instead of the 12th? Will we ever meet again? In one case at least, No. Too much trouble to put up with.

In school, when an assignment is distributed. And I read it, what if it makes no sense? So I *do* go to the instructors office, and I do ask for clarification — I get treated like chopped liver —.

Professors who know that I'm dyslexic grade me harder, and give me a lower grade than they would otherwise. why do I tell them? Because I need extra time to write sometimes, or don't

want spelling to be held against me. I've never told a professor that I am L.D.* without them first having asked me about my "rude" spelling or some such direct question. I can't use a dictionary. They don't get that I can't begin to form the sequence of letters in a word — I know it when I see it — But its spelling is as inaccessible to me as the variable name of plants is to most people.

I attended a class all term, I took the final exam, three hours of writing, and looking at slides, and identifying the problems of a housing development or a shopping center from one slide. I got 95 out of 100 on that final, but for some reason, got only B- in the class. When I spoke to the instructor, she thought that I was not capable of entering grad school — telling me that only the most intelligent people could be grad students.

She said *that*, seeing a fat woman, whom she knew to be dyslexic. She knew because I had to present letters to her telling her that I was L.D. because otherwise spelling would count against me on the exam.

Or what about when my dear friends laugh at something I say that is a mistake — even if they think it's "cute?" — what about if they repeat it? What if they think it's cute and always repeat it to me? I'm lost — I can't find my way — I mean I want them to like me and to feel close to me, and perhaps repeating my mistakes or oddities to me is a way of showing approval and acceptance. But to me it feels a little like imitating a disabled person's faltering walk to show that you think it's sweet —

But what of the positive virtues of being dyslexic or L.D.? For there are many — I see; I can lie in my bed at night, and in a dimly lit room, see the molecular pattern of the atmosphere in my room. you don't believe me — I see the halos around birds, cars, airplanes — I see the energy egg surrounding trees, Halos, rainbows around street lights and car lights. I look into the sky and I see the stars wheel, their trails of centuries arcs and crosses and paths, and then the sky quiets and it is all as it is for every other observer.

I can listen also: I can listen to the heart of the weather — and I can travel between science and art, and different sciences, to

* Learning Disabled

understand how molecules in a body work, or show the universe is moving.

I taught physics in a high school last year — relativity, and music. But I can't spell, and I can only do math very slowly, and then only if no one talks to me about it.

Dyslexia is a physical, not psychological, disability. The grey and white cells of the brain, which are arranged in columns in most peoples (heads brains) are randomly arranged in some dyslexics brains. The connections are different. (So I move slowly — I am moving though so much uncoded information.)

For some people who are physically disabled, life is trying and frustrating, in part because they want to continue to be jobs and can not get their bodies to cooperate. Despite the fact that they may be also in much pain or discomfort, at a particular moment, they may be most frustrated because they can't play 2 hours of ball. Their will to play is still as strong as it ever was, and their understanding of the game is better than ever, but their body won't cooperate.

Well for me — it's my mind — it is as though it is perpetually caught in chains or a large net. I can think clearly, and I can understand most anything that comes my way —

For example, I once invented in twenty minutes, a solar operated water purifier, portable that would convert sea water to palatable H₂O, and be self cleaning. But this same mind is in chains — I can't speak clearly can't remember the name of things — Make up words that do not exist.

In my field of Architecture, I can't draw it all either. I don't remember how to make my hand go — so I go slow — and I repeat myself because I don't really know if you're paying attention or not, and I don't finish my sentences — Because the finish seems obvious. So you, whoever you are who might be listening, get bored or annoyed and tired of me and I can't help it.

I am too strange, too needy, to be loved. And I am too alone to change. That's why, at age 40, I can't stop crying.

I have often wanted to stop living. I have felt that I could do nothing to change myself or my circumstances. I go on because I have felt that I could not be so inconsiderate to my children as to kill myself. Perhaps this is an excuse, and certainly other wimmins' lives' are valuable without children.

More ...

What I really hate is when instructors will discount my dsylexia — For example if my lines consistantly don't meet when I am drawing, and I know that it is because I'm dsylexic and to make lines meet without crossing is a major effort for me. My hand and eye don't move together as a team. Any how here I am in a studio class room & the instructor is saying your work is sloppy — and I say — oh. I'll fix it up, it's because I'm dsylexic. and the instructor says — No such thing — Its just lazyness — Take more care.

Or in an English class, my paper written in class is given a low mark — I ask the instructor why? He says the spelling — I say what about the content — oh he replies the content was great, very good, one of the best I've seen on that issue. Well I'm dsylexic, I can't spell, its physically impossible for me and I can't use a dictionary —

Well, I don't give a special break to Blacks or people in wheel chairs — & I can't give you a break either.

Or in a library, I go to the reference librarian and explain that I need to find a listing for something. I tell her that the card catalouge is difficult for me. The words seem to float up off of the card. I explaind its difficult to read, that I have a hard time with the periodical guide. She is all kindness and helpful and asks a little about what I need. Then she brings me a huge closelly written book wich is a list, three colums wide, on flimsy leaves.

Not all dsylexics have developed social problems as a secondary reaction to the inaccessabluty of the environment.

Some have developed an inability to see how to order their own lives. You will see these womin ministring to others, helping them to get things done or to understand their feelings — but they can't seen to find a path or way for themselves. This is common to women you might say. Many women don't know what their life work *is* — But given 2 wimin of the same gifts and skills, the one that is dsylexic will not have been able to obtain enough clear feedback, *for herself*, about what pleases her to do, to be able to make an evaluation of what she is suitable for.

Ayofemi Stowe Folayan

Dyslexia

dedicated to Helen Irlen

Words

bobbing like boats
afloat on a shimmering white paper sea
crushed together on cresting waves
foaming and swirling
sailing slowly out of sight

Each letter with its twin
snaking in inky trails along the page
grinding understanding
to a fine choking dust
that suffocates my mind

Words

lost in thick grey cloud formations
and chalky nebulae of stars
on the slate board
carried in sealed time capsules
drift beyond my understanding

Numbers

unintelligible Sanskrit
playing hide 'n' seek
dancing around each other
changing partners
in a joyous celebration I can't join

Thoughts

wait patient as grazing cows
no cowherd to lead them home
only tall fences and stone walls
blocking their passage
keeping them far away

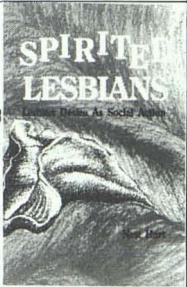
Eyes
itching and burning
blood vessels like welts
whipped into their straining surface
tears evaporated
leaving a salty sandy desert

poking out of my head
useless periscopes
that never pierce the waves
where the words still float
like senseless carcasses

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from an untitled essay in progress

...I continue to write about disabilities and so-called "hidden disabilities." All disabilities cannot be easily categorized as either hidden or visible, though, as there are different degrees of visibility from condition to condition. My condition manifests itself differently from person to person and can change over time or even from one moment to the next. The nature of my disability is often unclear to "outsiders" and, even if it is apparent that I'm differently abled, even persons who try to may not be able to determine what needs I have. At such times my needs are more hidden than my disability....

Meeting my day-to-day needs isn't easy. In this country there seems to be an attitude of "you're not getting anything special until you prove that you need it," and my varying ability to pass as able-bodied increases the burden of proof and need for explanation. Proof is required for everything from financial assistance to handicapped parking permits. The demand for proof is often accompanied by the fear that people will take advantage of the system, and anyone who receives anything "special" is looked upon with suspicion. Governmental agencies, therefore, require participants of certain programs to verify their eligibility repeatedly. I've had my share of frustrating battles with government agencies, but I may be more disheartened by the struggles with people with good intentions who still demand proof, explanation. Women who think that handicapped parking is only for persons who look disabled, for example, are trying to be advocates.

In an ideal society, one would only have to say what she needs to get it — or perhaps not have to ask at all....When we create temporary women's space some women may be so involved in the patriarchal culture that they've internalized some of its values. Even the attitude that disabled women are somehow not fully human is found in women's space. One time I was leaving women's space in a van for differently abled women. The van stopped for a woman who laughingly asked the driver, "Can you

ride this bus if you're normal?" She didn't seem to understand when the driver asked her to be more sensitive to the other riders.

That women are attempting to accommodate differently abled women at community events gives me hope. However, even necessities are sometimes denied because to provide them would be "impractical," as if services for differently abled women are optional. If services for differently abled women are considered optional, my needs can be ignored even if I don't have to explain them. And, of course, if it's too impractical to provide these "optional" services, it'll take more than asking to get them. The demand for proof and explanations must be eliminated, and services for differently abled women should be seen as essential and indispensable. We need to change attitudes so instead of asking why a service is needed, we ask why it isn't already available.



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from *We Are the Canaries:*
Women, Disability and Coalition-Building*

For the past five years, Susan Koppleman has been nudging me to deal with my identity as a disabled woman. And for the past five years, I have refused. I was too embarrassed, too afraid of the stigma, too afraid of its threat to my professional identity. Too afraid that naming it would give it control over my life.

I have spent the past fifteen years as a radical feminist, a Marxist, a lesbian, a fighter. But this is an issue that I have been terrified to take on. To speak about disability renders you vulnerable to the charge of hypochondria and malingering. Or maybe — even worse — of being needy....

I have immune dysregulation. It is a life-threatening illness, and I have spent the last five years denying that fact. Pesticides, sulfites, chlorine, food additives (for that matter, most foods), hormones, phenol, formaldehyde, gasoline, cigarette smoke, perfume and tar are among substances which can cause a sudden gross fluid imbalance in my body. When it affects my head, I get fluid in my brain. *It hurts.* I also can't think straight. When it attacks my joints, I can't walk. When it attacks my lungs, I can't breathe.

When I come to this conference, I have to take all my own organic food, spring water bottled in glass, and all my own 100% cotton bedding, laundered in baking soda. To get on the plane, I have to take shots of ethanol, perfume, and cigarette smoke. *It's inconvenient.*

Every year, I have to write to the conference organizers and arrange with them for me to be able to bring my own food into the dining hall. This year, I was told that under no circumstances (because of an Illinois state law) could I do that — even if I paid for a dining room ticket and ate none of their food. The director

* From a paper given at the National Women's Studies Association Conference, 1986, excerpted and slightly altered with the permission of the author.

of conference housing's solution was that I could eat all my meals alone in my room. I was not to bring food into the dining room — not even the only unchlorinated water that I am permitted to drink...

Women with disabilities and chronic illnesses have the same rights as able-bodied women to enjoy the community, conversations, and friendship that accompanies breaking bread together.

In the past year, I have considered civil disobedience around issues of divestiture, nuclear politics, and Nicaragua, and have rejected it only because my health — in fact, my life — would be jeopardized if I were jailed.

As I was being threatened with arrest in the conference dining room for sneaking in my own food, Merle Woo quietly reminded me of those who went to jail in order to force the movie theaters and the buses to allow people with wheelchairs access. Suddenly I saw that disability was not just my own private struggle.

Accessibility, integration into society, the right to a decent and free education and to quality medical care, the right to control over our own bodies — including full reproductive rights — the right to jobs, decent working conditions, and a living wage: these are our demands as disabled women, and they are our demands as workers, people of color, lesbians, socialists, feminists.

...Disabled women as a group live under an economic and political system which is often directly responsible for the disabilities inflicted upon us. As Heidi Durham noted, "The only thing this government has consistently and conscientiously done, in fact, is to help big business profit — enormously — from our disabilities."*

We are the so-called consumers of social services. Which means that our mistreatment is the source of employment for many of you, and our situation is identified as the burden of social security and as the source of your high taxes. Most of us are poor. Only 42% of us are employed. And 75% of those who *are* employed are underemployed and underpaid.

...You think that being polite means not meeting our eyes if you see one of us in a wheelchair, or with cerebral palsy, on the

*Heidi Durham, *The War On The Disabled: Adding Insult to Injury*, Freedom Socialist Publications, 1987, p. 2.

street, or in a restaurant, a movie theater, or a concert hall.

You don't think we're pretty.

You don't *know* we're sexy.

...We in the disabled community have learned to identify our strengths, our wisdoms, and our role as ground-breakers for the feminist community. Now that we know we have at least as much to offer the able-bodied community as you have to offer us, we are willing to risk becoming visible and articulate in your midst, demanding that you listen to us and learn from us and work with us....

But you better listen good and well, because we don't want to have to waste a lot of time saying it over and over. *We want to get on with our lives.*

We need to make it more and more safe for women who are disabled and chronically ill to publicly say so.

We need to have fun together.

We need to see that while NOTHING about oppression is beneficial, RESISTANCE to oppression teaches us, enlarges us, engages us....Resistance to marginality, to otherness, to invisibility, to silence, is the agenda of all oppressed groups, all suppressed peoples. And it is an agenda which can help to keep us from being fragmented and alienated from one another.

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On Ward G

The clock on the wall over the nurses' station says 5:05. I forgot to bring my watch when I left home at 1:30 a.m. to drive myself once again into Emergency at Kaiser Hospital. My asthma is especially bad this time, and again it's happening when I have my bloods. I wonder what the connection is.



There was a patient in the waiting room smoking a cigarette when I arrived. She was holding it down below the eye level of the receptionist and sort of cupping it in her hand. I could smell it the instant I opened the door. Someone was also wearing very heavy perfume, the receptionist, I think. I stood in the open doorway, gasping for air as I got up the nerve to speak to the woman with the cigarette.

"I'm having an asthma attack," I wheezed at her, "and I need you to put that out."

She put it out but not before grumbling some obscenities under her breath. She looked pissed as hell. Then, when the nurse took me ahead of her, she was really steamed.

"How come you're taking her first?" she complained, "I could be dying of pneumonia out here."

The nurse just told her it was because I couldn't breathe. That's all I heard anyway. I didn't blame her for being pissed, but I sure was glad they took me right away, cause I was real sick this time.



The young doctor on duty was the same one who had seen me last night and he remembered me. This time he looked sort of scared. Not the nurse though. She was totally cool. She just kept working real fast, zipping those needles into my arm and saying "stick" just before she jabbed me. That juice they shoot me full of is a speed freak's dream. But me, I don't like that high, nervous feeling it gives me. It reminds me of all those years I was on diet pills as a kid. I used to feel like climbing the walls. I never learned to like it the way some people do.

The nurse stuck me a bunch of times and gave me a treatment on the breath therapy machine. They took my blood pressure which was really high. That usually happens when I'm having an asthma attack. They don't volunteer the information about how high it is, but I always ask. They have to tell you now, it's the law.

The medicine was making me shake a lot. My teeth were rattling in my head, but the wheezing just stuck with me. I knew it would. I could tell the doctor knew too, but they have this procedure they have to go through, so we tried all the things first that we both knew weren't going to work. Then the doctor told me I'd probably need to be on IVs and stay the night on Ward G.

That's the name they use here at Kaiser for the holding ward. It's a kind of Never Never Land between Emergency and one of the regular wards. They keep you on G hoping you'll get better in 8 or 12 hours and that will save them the trouble and paper work of admitting you to the hospital. I'm an old hand at Ward G.



The best things about being on G Ward are they give you a real bed which is a lot more comfortable than a gurney, you get a table across the bed so you can write and the nurses don't smoke on duty like they do in Emergency.



It's about 6:00 a.m. now. There's a voice coming over the loud speaker saying, "Code Blue, room 620." She has said it three times now, real calm and gentle-like. "Code Blue, room 620," she says, like nobody's gonna know that someone in room 620 is probably dying. Now she's doing it again! What's wrong? Isn't anybody responding? God, I hate how helpless I am in the hospital, how dependent. She's saying it again! *Please, will someone go to 620 already? I can't stand the pressure.* OK, she finally stopped. I hope they got there in time. I'm afraid tonight, more afraid than usual, of dying.



I was saying before what's good about G Ward. The best thing is having a bathroom right near the bed, just a few yards away. In Emergency if you get put in one of the rooms where they put the sickest people, the bathroom is a city block away. And since they put me in this stupid night shirt, or whatever you call it, that closes in the back and only goes half way around my fat body, my whole

back is exposed. I have to walk through the hallway dragging this IV pole and my backside is sticking out for everyone to see. The halls are always filled with patients and their friends and family and various staff people. It's really too much.



Now for the bad. The worst part for me is that G is where the staff refrigerator, microwave and coffee machine are. Doctors, nurses, aides, maintenance men and security guards are coming in every few minutes, getting food and coffee and yackin' up a storm. Real early this morning there was this big box of Colonel Sanders Kentucky Fried Chicken in the refrigerator, and each staff person came in, took some out and put it in the microwave. The smell of greasy chicken was all over the ward. They kept taking out potato salad and cole slaw and apples and juice and milk. I'm in the bed right across from the refrigerator and I'm starving. I want to ask for something to eat, but I know it's for the staff. They don't feed the patients during the night. If I were a thin woman I'd have asked for some anyway, but I didn't want to provide them with a funny story about the fat lady who wanted their food.

I've been up for 48 hours now and it's been over 12 hours since I last had anything to eat. In a few hours they'll bring me breakfast. I can guess from experience what it will be: an asthmatic's nightmare! A cheese omelet, Wonder Bread with butter, a glass of milk, and some apple juice. Everything that makes me wheeze more. I'll eat it anyway, whatever it is. They don't know a thing about nutrition and diet for allergies. I wonder what they teach dieticians in all those years of schooling.



For a while there last night I got real scared. I don't know why except it was unusually hard for me to breathe and suddenly it occurred to me that I might die tonight. I flashed on this scene from the movie *Resurrection* where this woman dies in a car accident and she goes to this place that's like a tunnel with bright light at the end. All her dead relatives and neighbors are there, welcoming her. Well, I began to feel like I might be seeing my Bubbie tonight, and I started to cry. I suddenly missed her so much. I never really let myself feel how much I missed her till now. I could see her in my mind like she was when I was a kid. She died when I was 11 or 12

years old. She was very short, maybe 4 feet 10 inches, fat and wrinkled. She had the finest, most pure white hair I've ever seen; a bobby pin wouldn't stay in it for 2 seconds. And she had soft brown eyes. When she looked at me with those eyes I knew I was loved. Even though she didn't speak much English and I didn't speak much Yiddish, we managed to communicate somehow.

I was crying and thinking about seeing my Bubbie and then I said, "No! I'm not ready to go yet. I still have more stories to write and more women to know and love. It's too soon. I'm only 47 and I just started living 10 years ago when I came out as a lesbian. It's too soon. I won't go."

Then I looked at the door to the hallway in the wall next to the refrigerator and saw this thick white tape spelling out the word "NO!" It was about eight inches high and I looked at that word "NO!" and I said to myself, "I'll just keep looking at it to remind me that I can't die today. For one thing, nobody knows I'm here."



I realized how alone I am when the woman in the next bed came in a few hours after I was admitted. Her daughter was with her, and it made me think about how I don't have anyone here with me, no family. I have friends and even a lover or two, but nobody I feel like I want to ask to drive me to the emergency or check in to see how I'm doing. It's easier this way. If I call someone they get all upset and then I have to take care of them and it takes more energy than just coming in by myself. So anyway I can't die tonight because nobody would know. I'd just disappear. Of course eventually somebody would see I wasn't at a meeting or didn't make a lunch date and they'd ask each other, "Have you seen Malka lately?" Sooner or later somebody would call the hospital and they'd be told I'd died days ago. Since the hospital has no information about "next of kin" they had just given me a pauper's funeral. You can't leave a smelly old body lying round indefinitely, you know. Anyway, I'm going to live this time, so it doesn't matter. Next time I'd better make some arrangements.



I almost blew it with the male nurse when I first came in. I mean it's as important for the patient to have the right bedside manner as it is for the staff. Even more important since we're talking about

survival here. I've developed a system over the past few years. The theory goes like this: The best of nurses is overworked and the worst just couldn't care less. The more you can do for yourself the better; that way when you do need to ask for something, they're more likely to be willing to do it for you. So I straighten my own sheets, push the red button on the IV machine when it starts beeping, get myself water, things like that. The other thing is that you have to be polite but not too polite, or they'll ignore you. The most effective method I've found is to be assertive and appreciative at the same time. For example, when I first came to G Ward tonight I realized I'd need some sanitary napkins. Now if I had been mealy-mouthed about it I'd have gotten them eventually, but the nurse might have been hostile and seen me as a simpering weakling, and done as little as possible after that to make me comfortable. So in a strong voice, level but not pushy, I said, "I'll need some sanitary napkins and some ice water and that should do it." He brought them to me right away and I smiled slightly, not too friendly but acknowledging the effort. Then he hooked up the IV bag to the machine. Now that's where I made my first mistake. Instead of just keeping my mouth shut I said, "I'll just unplug and take this in with me when I need to go to the bathroom." "No," he said, "you have to call me each time, and if you have to go too often we'll have to give you a bedpan. The doctor put you on bed rest."

"Well," I thought, "we'll see about that, Honey. I'm not using any goddamned bedpan as long as I'm conscious." So, I'd just quietly slip out of bed and slip back into bed when I was done and plug back in. I think by the third time he must have realized what was happening. He just ignored it.



It's after 9 o'clock now. Around 7 a.m. I could hear the night nurse filling in the next shift, but I couldn't see who she was. When I finally did see her I knew I had my work cut out for me. It was Sharmina, tough as nails and slow as a snail. Not only that, but I was so hungry by this time I could have eaten the bedclothes, and Sharmina has this thing about taking her good old time about feeding patients, especially about feeding me.

The first time I was on Ward G, about a year ago, I made the mistake of telling Sharmina at 7 a.m. that I was hungry. I ate around 10 a.m. that time. Now I know she's fat phobic and I have

to charm her to get anything at all. So when she came to check my IV around 8 o'clock I smiled and said, "They could use three more of you on this shift. They sure do give you a lot of work to do." She smiled and then I said, "I love your ring." She liked that. I got my breakfast about 8:30.

Manipulation sometimes doesn't hurt anybody and it can help me survive. I wish I didn't have to do it. I'm not sorry I did though, even if I was right about the breakfast. It was worse than I had expected — French toast made with two thin slices of Wonder Bread, two soggy bacon strips and a carton of milk. There were two orange slices too, which had been heated with the French toast in the microwave. I ate them anyway. I was tempted to pour some of the honey-cinnamon syrup on the styrofoam dish and see how that would taste, but I squelched that idea. I can't afford to die of styrofoam poisoning when I'm in the middle of writing a story. I left the milk and the dish and ate everything else. I'm still starved. Maybe later I can get someone to come over and bring me some real food.



It's now 9:30 and the doctor who came in at 9:15 said I'm not sounding very good. I could have told him that. They can only keep me on G Ward till noon and then evaluate whether they should admit me or send me home. Either option scares me.



I'm feeling really uptight now, scared, pissed, wheezy and panicky. About half an hour ago I phoned my boss to say I'm in the hospital and I don't know if they are going to let me out or not. She sounded tight-lipped, not happy at all. "So what does that mean?" she wanted to know. I said, "Well, I'll know around 12:00 or 1:00 if they're letting me out or admitting me and I'll call you then." She just said, "OK, let me know when you know." Then she hung up.

I spent the next 5 minutes doing a scenario in my head, a confrontation where I go to work and she says to me, "Now look, I want to be fair, but I have a business to run here and you're missing too much time. I know you haven't used all of your sick leave, but you're out when I need you, and it's really a problem." So I say, "OK Carla, what exactly is it you want me to do?" and she says, "I just can't have this. I need to be able to depend on you. I

want you to be here when you're supposed to be here."

"You're saying you don't want me to be sick and miss work, right?"

"Well, yes, I guess so"

"OK Carla, I won't be sick any more."

"Now wait a minute," she says, "How can you promise you won't be sick?"

"It's just as reasonable for me to promise," I say, "as it is for you to ask me to." I leave her on that. She's very guilt-ridden and liberal as hell. She also has a lot of power over my life. She pays me a good hourly salary and gives me holidays and sick leave, but she won't pay into unemployment or disability so I'm at her mercy. If I lose my job or become physically unable to work, I'm out of luck. So I'll come in to work as much as I can, unless I'm really dying. Meantime I think I ought to look for a job where they're not so nice but where I can get unemployment and disability benefits. I feel really sad. I hope the fantasy doesn't have to be played out all the way. I like working for Carla.



Around noon Sharmina comes over to my bed with a big syringe full of medicine and she starts to inject it into the IV tubing. I say, "Wait a minute, what's that?" She says, "It's just some more Solumedral." "What do you mean 'some more'? What is it? Is it steroids?" "Yes," she says, "you've been getting it all night and it's time to put in some more." Now I'm pissed. I say, "Nobody told me they were putting steroids in the IVs. I specifically asked in E.R. to be told if they were going to give me steroids." "Look honey," Sharmina snaps, "I can't control what they do or don't do in E.R. I'm just giving you what the doctor ordered." I want to cry. Damn them, those arrogant, fucking-bastard-prick doctors.

I decided to let myself cry. I was just getting into it, allowing the tears to splash onto the blankets when this doctor I hadn't seen before comes by to make his rounds. It's been hours since I've seen a doctor, and just when I'm trying to have a good cry, he shows up and says, "Why the tears?" "I'm really angry," I tell him. "I just found out they're giving me steroids. They promised they'd tell me before they did that. I wanted to check with my own doctor first. I've been on steroids for 5 months now and I've been cutting down, trying to get off them. Now they've upped my dose and I'm

really mad that I wasn't informed like I was promised."

"Well," he says, puffing himself up to his full height, "if you've been on them for 5 months that's all the more reason to increase them if you're having an attack."

I'm not convinced. "I'm angry about not being *told*," I say. "What's at issue here is informed consent. I feel totally out of control of what's happening to me."

"Now, now," he says, "we're giving you the best treatment we know how." Then he leaves as suddenly as he arrived.



I'm chewing on that last piece of drama when Maude, the nurse who's now assisting Sharmina, arrives and sees me writing in my journal. Are you keeping a diary?" she asks. That's when I made my second mistake of the day. "No," I say, "I'm writing a short story. I figure something ought to come out of this experience." The minute it's out of my mouth I know it's a mistake. I don't know how it will come down, but I know I'm going to have to pay for that one. Maude doesn't disappoint me. Next thing I know she's coming over almost seductively, placing a thermometer in my mouth and saying, "I hope you're putting good things about the nurses in your story."

"Of course I am," I answer quickly. "The nurses are the best thing going around here." The next thing I know she's telling me how she's trying to lose 15 pounds. I mean I'm sitting here in bed, all 300 plus pounds of me, and this 5'-9" woman who weighs maybe 150 or 160 at most is telling *me* that she's on a diet. Now I don't want to hear about it, but I'm not in such a favorable position here. I don't want to make things worse, so I just say, "Why are you dieting? You look fine to me." "Oh," she says, "I need to lose 15 pounds. I lost 50 pounds not so long ago. I got down to a size 3 and I felt soooooooooo good. But then there was all this food around. You know I hardly eat anything at home, but here at the hospital they give us free donuts every morning, and I just keep eating. I gained back 15 pounds so I have to lose it." All the time she's talking she's acting real coy and charming in a way she wasn't doing before. I say to myself, "Hey now, what's going on here?" Then suddenly it comes to me. She's auditioning! I mean she wants me to write about her in my story. She keeps coming back

and talking to me every few minutes. At lunch she gives me an extra roast beef sandwich when I say I'm really hungry. Now this is unheard of behavior from my past experience. So she wants to be in my story? OK, so she's in my story.



It's 2 p.m. now and I want this story to end, but it keeps going on and on. I'm getting very exhausted and I feel worse than I did when I came in last night. I'm breathing better, but I'm feeling sicker somehow. My hands and legs ache especially badly, but really I'm in pain all over. I think it's from the medicine they're giving me. Another doctor came by around 12:30 and said that the other doctor had told him I was upset. He listened to my complaints and said I certainly had reason to be upset. I should have been told what medicine was being given to me. He thought I'd be going home soon and he wanted to get a white blood count to see if I had an infection. He looked into my eyes and at my tongue and listened for a long time to my heart. Then he asked if I felt nauseous and I told him I didn't. He seemed very concerned. I'm sure he's the staff P.R. person, the one they send in when they're afraid of a lawsuit. He's got that smooth "I understand just what you mean" kind of manner specially suited for disarming and defusing.



It's 2:45 now and the P.R. doctor just gave me the word that I can leave. I'm relieved. I think one more hour of this and I'd be screaming and tearing the place apart. My head is aching. Earlier this afternoon I heard a nurse from another floor saying they had just sprayed for ants on her ward and all the patients are complaining of headaches. On top of that the cleaning woman has just left after mopping the floor around me with some foul smelling disinfectant. Chemicals of any kind make my asthma worse. So now my head aches and I'm starting to feel dizzy and wheeze more than I had before she came.



It's 4:00 p.m. and I'm home now. As I was leaving I gave Sharmina a little hug and told her, "Hey, let's get together socially sometimes. I don't want to have to keep meeting like this." She just laughed. She's really not so bad. Kind of cute, in fact. I hope I never have to see her again.

The Swooner (the bedder)

Kissing fifteen minutes
I wrestle your shirt
your Brand New Third Date Shirt
until it lies in a heap
on my hardwood floor.

You call me Fast.
I'm not.
Only desperate
to get your shirt off.
This isn't passion choking me up:
it's formaldehyde.

Naja Sorella

A/part of the Community

I'm a Lesbian sick and tired of being sick and tired. I'm a Lesbian sick and tired of being chronically ill while Lesbians put their physical, emotional and financial energy into AIDS. Here in the dyke community immune system illnesses are knocking large numbers of womyn on their butts, sometimes for life.

Environmental Illness (E.I.) (also known by dozens of other names such as Chemical Hypersensitivity, Complex Allergy Syndrome, etc.) and Chronic Fatigue Syndrome (also known as Chronic Epstein-Barr Virus Syndrome, Chronic Viral Syndrome, etc.) have been sweeping through the Lesbian community for roughly the same amount of time AIDS has been hitting the gay boys. While these illnesses are due to damaged immune systems and can totally incapacitate for life, they rarely lead directly to death. Death is what makes AIDS so popular a cause. AIDS is a killer! It's striking people down in their prime! Such a tragedy early death is, such a tragedy! People respond to this type of drama. Early death is a tragedy, but equally as tragic is a lifetime of being too ill to rise out of bed. And both E.I. and Chronic Fatigue can do this.

E.I. literally makes people allergic to the world, because damaged immune systems can't deal with the chemicals in everyday products. All personal care products, car fumes, smoke of any kind, carpets, synthetic clothes, all cleansers and laundry products as well as most foods head the list. Severely E.I. people can't leave their homes and/or let others into them. Some even need to strip their homes of everything but a few cooking utensils, a porcelain bed with cotton blankets making up the mattress, a few cotton clothes, and safe drinking water. They don't open their windows or doors as the air makes them seriously ill. Chronic Fatigue symptoms can include cellular exhaustion, debilitating weakness, neurological problems, muscle and joint pain, sore throats, sore lymph glands, nightsweats, headaches you wouldn't believe, poor memory, lack of concentration and other thinking problems, as well as severe depression. Damaged immune sys-

tems leave the body vulnerable, thus most of us also have other types of auto-immune and viral illnesses, such as candida and thyroiditis.

There are other immune system illnesses that are devastating to Lesbians, such as lupus, M.S., arthritis, cancer. I've concentrated on E.I. and Chronic Fatigue as they tend to be disregarded by both society at large and the dyke community as not "real" illnesses. Since we're not viewed as "really" ill, in turn we're not offered the same support on all levels that people with "believable" illnesses receive.

Step one is to educate yourself. There are numerous articles, newsletters and books on these illnesses. Listen to what we tell you these illnesses are about and what we say we need around them. Those with E.I. and Chronic Fatigue are often told it's "all in their heads" by doctors. We don't need to hear this from you as well. Realize that both E.I. and Chronic Fatigue vary widely in their effects and just because you've known a woman with these illnesses doesn't mean you know what it's like for the next woman. One woman assured me I'd get well from Chronic Fatigue because her friend did after having it for a year and a half. Telling her I've had it for six years, and that most of us who have it more than two years don't recover, didn't move her from her conviction. Don't make assumptions about these illnesses, ask us what we need, listen when we tell you!

Step two is to make your individual self and the dyke community accessible to us. And this takes work! We need dykes willing to change their personal care products to ones we can tolerate (called "safe" products) so that you can come into our homes as friends, lovers, attendants, doctors, acupuncturists, etc. I know many homebound women with no one willing to use safe products. I'm lucky, I have my E.I. dyke support group that meets at my home, my lover and one friend who use safe products. When you tell us you just can't give up your mousse or fabric softener or you just have to have brand X for your face, you're telling us a product is more important to you in your life than we are.

Smoke, perfume and other scented products (including chapstick and gum), carpets, cleaning products, animals, etc. keep us from your homes and social events as surely as stairs would keep out a wheelchair-bound dyke. Realize that E.I. dykes are every-

where, some of us try to go all the places you go: the bank, grocery store, doctor's office, library, concerts, the local dyke hang-out. Your herbal scented oil, hand lotion, laundry soap or styling gel may be making us sick. If we don't say anything, it doesn't mean we aren't affected. It's difficult to constantly be confronting people about their toxic products; those products have already made us ill and many people react with hostility. If we do tell you, don't deny our reality by saying you having "nothing" on. The natural oil you used yesterday, your hair conditioner, or the liniment for your pulled muscle may be the "nothing" causing headaches, nausea, muscle weakness, breathing difficulties or dozens of other symptoms. We need you not to argue with us, we don't go telling people they're making us sick because we have nothing else to do with our time.

We get tired of doing all the work. If a woman indicates you're making her sick, ask if she needs you to move away, and how far. If you're at her home, offer to shower with safe products. If you smoke, be aware that smoke is highly toxic and more and more people are becoming sensitive to it. Smoking in public keeps those who can't tolerate smoke out of public places. If you do smoke in public, be responsive to requests to put your cigarette pipe, cigar, out. Moving away from us doesn't help, smoke travels. Many E.I.'s will react to the aura of smoke around you even if you're not smoking in their presence. Showering or bathing with safe products, putting on fresh clothes laundered in safe laundry products and not smoking afterwards can make you safe for many E.I.'s.

If you are friends, in a group, or co-workers, ask what she needs in order to be around you. Offer to use safe products, wear cotton clothes, put the cat out, vacuum before she comes, or whatever will make you, your group, the workplace, accessible. Confusion is one of the many brain reactions E.I. people have to toxins. If she isn't able to answer you right away, talk with her later.

Plan parties, workshops, conferences, events so they'll be accessible — invite us and ask us how. All ads should state that there will be no smoking, and request no scented products. Air purifiers may help. Print a phone number for access information on all ads — we may not try to come if we can't find out how accessible an event is in advance.

Think of creative ways for womyn to be part of your group whether they have these illnesses mildly or severely. A womyn with mild Chronic Fatigue may be able to attend a meeting but may need to lie down, or have the meeting be short. Homebound womyn may need other alternatives: participating by mail or on tape, having womyn agree to make themselves safe to be in her home, using speaker phone systems. Start asking around among your own friends. I'm sure you'll find disabled Lesbians needing your kind of group, whatever it is.

Step three is: give us the same kind of support you give AIDS. If you do grief work for AIDS patients, do it for us. We're in continual pain over the loss of our bodies, our loss of functioning, our isolation. If you donate time to an AIDS organization, at least donate an equal amount of time to a dyke with an immune system illness. We don't have caregiver groups set up to come in and wash our dishes, clean our houses, take us to the doctor, do our laundry, go shopping and fix meals. Not all of us are on SSI and/or have attendants. Those who have attendants are usually in need of much more extra help. If you have a skill such as massage, acupuncture, homeopathy, chiropractic, etc. and you're thinking of donating it to AIDS patients, give it to a dyke instead. Since many of us are homebound, be willing to come to our homes. If you give money to any types of AIDS organizations, give it to an ill Lesbian instead. If you give activist time to AIDS political groups or causes, give it to groups dealing with these immune system illnesses that affect mainly womyn. You may even have to start your own. These "women's illnesses" haven't seen any influx of big bucks for support services or research.

Accessibility requests from womyn with other types of disabilities don't usually require personal changes from dykes. Ramps, grab bars, ASL, braille, don't require womyn to make changes in their personal habits. The changes we ask for are not options for us any more than ramps are options for womyn in wheelchairs. Lesbians with E.I. and Chronic Fatigue often end up totally isolated, viewed as either "crazy," or controlling and manipulative. These illnesses are seen as too much of a problem, we ask for too much, we're too much hassle. We ask for changes for the same reason womyn in chairs or deaf or blind womyn ask for changes: so that we can all be part of the community.

Shemaya Mountain Laurel

from On Becoming A Thin Woman

I used to be a fat dyke, quite content with the situation. Now my immune system fusses at food, my back fights cooking, and all in all the results of eating are often more uncomfortable than hunger. This has been going on for quite some time, and the effects become gradually more apparent. Though it's not as bad as it could be; I shudder to think where I'd be now if I'd started off thin.

...Twenty-five years of being fat informs my life, and thinness is not coming easily. For one who prayed for anorexia, it is high irony that now, twelve years later, I am upset at becoming thin. I remember, in the time when I was almost but not quite finished with dieting, feeling heretical at my touches of sadness at the loss of my body. A neighbor, as a form of the familiar diet congratulations, exclaimed, "There's so much less of you!" The thought stayed with me, that part of the essential "me" was being lost.

Now, I read speculation that "mind" is not located in the brain. Rather, it is all through our bodies, intimately connected with each cell. The source of "body memory," whether incest or a long unpracticed song on the guitar, still "remembered," if one can only relax and let it play itself. And I wonder: where does that leave the person who loses a part of her body? Whether through accident, surgery, or an overall diminishing of flesh? Is part of the wrenching pain a sense of the loss of "mind," along with part of one's physical self?

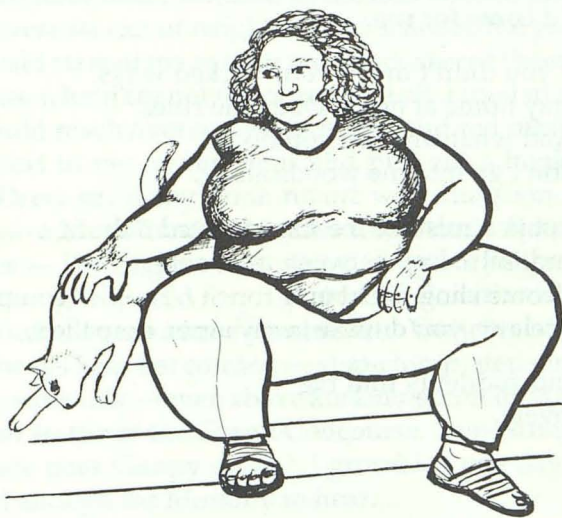
...I've become known for being touchy. People "compliment" my loss of weight, I say "illness, was happy how I was," etc. and show varying degrees of aggravation at their implicit statement about what they thought I looked like before.

...Increased sexual messages from dykes who knew me before are insulting. It's interesting information to have, but I'll stay with the womyn who appreciate my attractiveness in ALL its forms.

...The hardest part in this is the shift in how fat women relate to me. Particularly those who've only known me thin, and especially those I meet only for a moment, or pass on the street. I

understand this, but am saddened by my shift in group. My attraction to fat womyn hasn't changed, and the loss of so much of my body is made sadder by the loss of being able to share it as fat woman to fat womon. I do mental work around perceiving the attractiveness of thin womyn, not wanting to rule out attraction because of having a hard time with pointy bones. I prefer round lovers, but don't want to be ruled by that ...

There is a solid, centered love of this changed body that I have yet to find; the key is most likely deeper than the fat/thin issue. Thinness is not the major change; it's only the most easily visible. The disabilities that are bringing it about are the real culprits, and my insides are screaming betrayal. If this body will no longer function, and its thinness is one of the marks, how can I love either one? I am trying to learn. ... But it's a slow process, this loving a new self. First come the introductions; I think I'm still at that stage.



Max Hammond Dashú

Boogeywoman

You would think the hump
and hairy chin would be enough,
but the scorn of others
has marked my face

like acid.

Warts thrive among my moles;
rheumatism gnarls my limbs.
Each time I lift my downcast

eyes, somebody cries foul.
I am the one who eats bad girls,
the one who drinks their monthly blood.
You were warned, someday
I'd come for *you*,

if you didn't mend your wicked ways.
Stay home at night. Obey the rules.
And whatever else you do,
don't go into the woods alone,

lest you mistake me for a twisted oak
and fall asleep between my knees,
after circling for hours.
At dawn you'd wake in my arms, enspelled,
and suddenly find me
lovely.

American Bandstand

I hated nice weather. My mother would make me sit on the stone stoop of our brown apartment building after the school bus dropped me off, while she gossiped with the neighbors. She said it would do me good to get a little sun — I was so pale and skinny.

"But Ma," I whined, "I want to go up and watch 'American Bandstand.'"

"It will still be on by the time we go up. Look, your sister will be home from school in a few minutes and I'll send her to the candy store to get you a chocolate malted." My mother was not above bribery.

So I sat listening to the droning voices being carried into the air as the women talked about the fruit in season at the grocer or the sale on bathing suits at Alexander's. I cooed at the babies awake in their strollers and felt pleased with myself that I could make them smile and laugh — they weren't old enough to know I was different. And I watched as the kids walked past in droves as they were let out of neighborhood schools, the younger ones who would stare at me as their mothers ushered them on and the older ones who'd try not to notice me at all. I tried to ignore it all.

I would reach over to my navy blue and red plastic bookbag sitting next to me on the steps and pull out a book, usually a Nancy Drew or, if my book report was due soon, one of the classics — a Mark Twain or Louisa May Alcott. Reading had its purposes — keeping me occupied and, by burying my nose in a book, I thought I could forget that Leslie Strom was on her way and I wouldn't have to see her snub me. Only it never worked. I could always hear her coming — step-clump, step-clump, on the concrete sidewalk — even above the kids' screechy voices and the heavy car traffic of the Grand Concourse. Step-clump.

"There goes Gimpy again," I grumbled one day to Shelley, not loud enough for Mommy to hear.

"You know her?" My sister was surprised.

"We ride together in the same van to the Carolians' on Saturdays. Yech." I felt much the same about the Carolian Club as I did

about the sun, but my mother insisted it was good for me to go. Yet if I had to choose between the two, I'd rather fry in the sun. "She never speaks to me in the van, either."

My sister offered compassion: "Hey, maybe one day, I'll run upstairs and throw a bucket of water out the window when she passes by."

I chuckled. Shelley could think such wicked thoughts. I wished one day she'd really have the guts to do it. I could just imagine Leslie caught in the cascade — her carefully combed flip flopping, while water dripped from her stringy bangs and down her upturned nose. It would serve her right — that polio gimp.

I didn't like her snubbing me, but I understood it. I was just letting my jealousy get the best of me. Oh, I wasn't jealous of her because she only walked with one leg brace while I walked with crutches and double-leg braces connected by a pelvic band — although my braces weighed about three times as much as hers. They only really bothered me when the weather was hot and the leather bands holding my legs in place stuck to my skin, or when, as a growing eleven year old, I would outgrow them every four to six months — the pelvic band would press into my hips and irritate the thin skin covering my pelvic bone until the readjustment could be made. Yet, besides holding up my knee socks, my braces gave me a steadiness, a feeling of security and brief moments of pleasure, feeling such heavenly relief and freedom when I took them off at night. No, it wasn't her brace or ability to walk better . . .

It wasn't that she was able to go to a neighborhood school, either. I got more attention in the special unit I was bussed to everyday than I would have in a regular classroom. All my teachers (of which I only had three since kindergarten) were very impressed with me, and why not? I was smarter and cuter than the other handicapped kids; in the sixth grade, I was reading at a high school level, and I was still blond and had a small nose. My mother always made sure I sparkled when I went to school in the morning (not that I'd come home the same way) — a little doll, they called me, since I was small and fragile-looking; they even remarked that when I sat still at my desk, you couldn't tell there was anything wrong with me. So what if the other kids at school didn't like me — the ones my age teased me because I was

teacher's pet, and the kids in my class — teenagers — didn't want a little squirt hanging around. No matter, adults were more important than those snotty kids; they appreciated me. If I went to a neighborhood school like Leslie, I'd just get lost in the crowd.

No, what really bothered me about Leslie was that she was acceptable — her, and the clique she hung out with on Saturdays. True, the girls were a little older — twelve or thirteen — but the fact of the matter was, older or younger, they could all do whatever they wanted to. They'd get permission to leave the clubhouse and hang out at the corner hamburger joint. They'd get the leads in every drama group production. And none of the staff ever "found" them when they hid under a stairwell smoking cigarettes. They were doing just what was expected of them, because they only had polio -- a mere inconvenience that surely didn't stop any of them from being average kids. After all, they didn't have to just sit still at their desks to look like there was nothing wrong with them — just sitting down ANYWHERE would do.

The polios — they were always at the top of the ladder, while I was on the bottom rung, because I had cerebral palsy (c.p.). The I.Q. tests didn't matter; any movements in your body that you couldn't control, speech that was slurred or slow, placed you on the bottom. No matter how I tried to climb up that ladder I still had the wrong disability. I hobbled too slowly to go with them to the candy store — even if they wanted me to, which, of course, they didn't. I'd lip a cigaret if I took a drag, since my mouth always seemed to have an excess of saliva which escaped down my chin if I didn't remember to swallow. And then there was drama ...

Drama was the one activity I wanted so desperately to be in. I knew I'd be good; I was such a natural — I could have a smile on my face even when I was miserable, make people laugh with my "wonderful sense of humor," poking fun at myself before others got the chance: "I walk so slow even the Tortoise could beat me in a race." I was a great actress — alone in my room — playing out romantic scenarios: princesses, captured by tyrants, rescued by handsome princes. I told myself my speech impairment didn't matter; when people really listened, it wasn't hard to understand me (my speech therapist even said so): if I were up there on stage,

my audience would have nothing else to do but listen.

Still, I wouldn't dare try out for a part. I could just hear what would be said about me: "She's making a fool out of herself, just like the rest of them." Then the head of the Carolians would get wind of it and note in my file: "The child is immature and has an unrealistic view of her limitations. She does not accept her handicap." Inevitably, the comment would appear on my school, medical and camp records and I would be lumped together with all the other c.p.'s. I couldn't let that happen. So, I proved that I was not only smart, but knew my place, too — I joined the club newspaper.

My mother's voice took me out of my silent lament: "Shelley, I want you to go get Neisie a malted."

"Aw, Ma, send one of the other kids, send Nancy, she's just hanging around," protested my chubby sister, slapping her books down on the stone stoop. "I told Harriet I'd meet her at her house."

It was always Harriet, or Alice, or Barbara. It was only me as a last resort — on weekend mornings when no one else was around. I knew she'd rather play with kids her own age but I was only two years and nine months younger and, I thought, a lot nicer than any of her friends — they were always so snotty. They'd only let me play with them on rainy days when their mothers gathered in our apartment to play mah-jongg.

The kids would go off into my parents' bedroom after the women chased them away for pestering them at the game. My mother, like the others, would be so glad to not have them breathing down her neck that she'd give the kids permission to do anything — play with make-up? "okay"; wear old dresses and high heels? "alright"; jewelry? "only costume"; and she'd call after them, "Let Neisie play."

On all fours — my way of getting around without my braces (a wheelchair was unheard of; my mother was afraid I'd start depending on it too much) — I'd half hop, half creep into the bedroom. They would be all dressed up in pinks and blues, fake pearls and rhinestones.

"Here," one of them would say, throwing the ugliest dark, ragged housedress over me. "You can be the wicked witch or the evil stepmother."

"Can't I be the fairy godmother?" I asked, already blinking back stinging tears.

"Nancy's the fairy godmother."

"You always let her be that," I pouted. They were always nicer to Nancy. Not that they really wanted to be — they were just scared of her mother: Pearlie could intimidate them with just one look. "Why am I always the evil stepmother?"

"Because we said so ... And if you don't like it, you won't play," came the final ultimatum.

It was no use looking to my sister for help; she stayed silent. I knew if I cried to my mother, she'd yell at Shelley, who would take it out on me. Besides, my mother was no Pearlie when it came to discipline; she'd just end up trying to make me understand, "Neisie, kids are cruel."

So, I played the evil stepmother, ordering them to mop the floors and wash the dishes. They, of course, ran away, clunking off in oversized high heels. I followed after them, trying not to get my knees black-and-blue thudding them down too hard on the bedroom's linoleum floor, or get splinters in my hands as I crept over the wooden hump of the doorway, or get rug burns from creeping on the living room carpet.

I couldn't keep up with them; my legs kept getting caught in the stupid old housedress. Soon, a familiar muscle in the back of my neck would go into one quick spasm, in protest of all my tensely driving motion. The cramp jerked my head back, lasting no more than a second or two, but the pain was so deep that it sent hot shivers up to my head and down my spine. No one was paying attention to notice, so I would just sit there until the funny tingling went away. All that remained was my headache, which had really started before the chase. I'd have to ask my mother for aspirin and then go lie down. Dress-up time was over anyway; the kids were playing 45's.

I had just slurped down the last of the malted that Nancy had volunteered to get for me because Shelley had gone off to Harriet's. Looking up at my mother's heavyset frame leaning against the stoop, I called until she heard me. "Ma? Ma?"

"What, Neisie?" Her head turned downward, but I couldn't see her face — the sun was in my eyes. "You're drooling, honey. You have to remember to swallow. You know what I always tell you?"

"Yes, Ma." I recited with boredom: "When someone says I'm cute and takes my chin in their hand and feels that it's all wet, they'll go 'blech!'" I made a horrible face.

"Right. And they won't want to do it anymore." She turned away for a moment to hear what a neighbor was saying.

"Good," I mumbled to myself, "let 'em keep their hands to themselves." Still, I wiped my chin on the sleeve of my furry, red jacket before my mother saw me. Otherwise, she'd scold me, saying that the saliva would ruin the fur. I always did it, anyhow, when no one was looking — too lazy to pull out the hankie from my pocket. I finished seconds before she looked back at me. She waited while I swallowed.

"Ma, can we go up now?"

She clucked her tongue in mild exasperation. "Well, I guess I ought to start making supper soon, so we can eat before Daddy gets home. Just let me have one more cigaret."

"But Ma, I'll miss Record Review." They sometimes had it in the first half hour of "Bandstand."

"Neisie, be patient," my mother mildly admonished. "We're going soon." I threw my book back into my bookbag, snapped it shut and waited. It took her forever to finish.

Putting the butt out on the stone stoop and throwing it out into the gutter (for the street cleaners to sweep up in the morning), she gathered my aluminum crutches, my bookbag, her purse. She held it all with her right arm and hand, leaving her other limb free. I offered my right wrist, which her free hand grasped. She pulled me to my feet; it always took me a few seconds to stop wobbling. Then, using her body to steady her arm as she held me, we started the climb — 22 stone steps on the outside, 20 marble steps to go once inside the hallway. By the time we were on the fourteenth or fifteenth marble step, the back of my legs would ache from the strain of carrying not only my own weight and the weight of my braces, but with the anticipation that in a few more steps, the grueling climb would be over.

Afraid that if I sat down on the kitchen chair, I'd be too wiped out to get up, I remained standing against the threshold of the kitchen and reached for my crutches propped against a nearby wall. Still catching my breath, I positioned the worn rubber armrests under my armpits and placed my hands tightly around the

wooden handles. I hobbled my way through the long foyer to the living room (always filled with the musty film of cigaret smoke) and into the rectangular, blue-walled bedroom that I shared with my sister.

Immediately, I went to the television corner to switch on channel 7 — “American Bandstand” — to be with Peggy and Justine and Bob and Tony and all my other friends. It didn’t matter that I wasn’t fourteen; I was mature for my age. I didn’t even play with dolls — I couldn’t dress them with all their buttons, buckles and bows.

While the TV warmed up, I leaned my crutches alongside the window and plopped down on the bed. A Clearasil commercial was on followed by station identification giving me just enough time to rest and wipe the sweat from my forehead. Then I stood up and, holding on to whatever was steady in between, inched my way over to the closet. Grasping the doorknob, I was ready for the next cha-cha to Frankie Avalon’s “Venus,” or Lindy hop to Connie Francis’ “Lipstick On Your Collar.” I thought I wasn’t that bad, either — keeping time with the one-two but leaving the cha-cha-cha (or else I’d lose the beat) and, of course, I didn’t swirl around too much during the Lindy. I sat out the slow dances, since there was no shoulder to lean on; instead, I’d sing along with the Platters’ “Smoke Gets In Your Eyes” — I could keep up with most of the words — and was proud that I was able to carry a tune.

What a relief!! No one stared. No one teased. No one disapproved — at least for the rest of the hour.



Breakup

Y
ou say you're tired of dealing with me
Tired of dealing
With these physical crises
I keep having
Over and over
With the way I never recover
Completely
With the effect that has
On my personality
You say
You're gonna leave me
Go off and start again
With some other girl
Well, shit
That sounds pretty good to me —
I'd like to try it, too.
I wanna break up with my disability.
Get a divorce
Sever our relationship.
I wanna move out
Close that door behind me
Take up with some new girl
A sweet girl
Who knows how to have some fun
One who treats me good
One who won't complain about her aches and pains.

Yeah, I understand the impulse to break up
And I envy you
Your options.

Snapshots of a Decade and More

In a discarded poem, I described it as the morning inventory/silent and internal. What hurts and how much. More important, how bad is the head?

The first few days in the hospital, I knew very little except that my roommates rotated constantly. They were there because they were expected to die and did. I was there for the same reason, but I didn't. In the emergency room, my face was stitched, layer after layer, without anesthetic while the attendants spoke about me in the third person.

When they brought in the x-rays, four hours after my arrival, my friend was allowed to come in. The doctors showed us the flattened marshmallow image which represented one of my vertebrae, now only 1/5 its ordinary size. In the reflection of the overhead lamp, I saw my friend slide off the stool and disappear from view, having fainted and fallen under the curtain into the next cubicle where a working physician hollered for assistance in removing the inert forms suddenly at his feet. It was the day's comic relief.

They moved me to another room and permitted visitors. My parents came in. I was still being asked if I knew my name and the year, and it became clear to me that they were surprised that I continued to supply the correct answers. I realized that my mind might not live even if I did.

For the first time in my life — probably because I believed it to be the last — I asked my mother for a hug. She said her back hurt and to ask my father.

The hardest part today is the unpredictability. On no day can I know for certain that I will be able to function the next day. The mobility impairments, when they occur, are not as severe as many

other disabled people experience. The wearing reality is that they might be there and they might not. Since it takes more planning to prepare for their presence than for their absence, it is the former which dominates my consciousness.

The accident was a fluke, even as motorcycle mishaps go. Another fluke was my being insured — a result of a part-time job I held at night, and some car insurance. Both policies allowed for double payment, which meant I could have the means of survival for a time. A friend asked me if I was really going to collect on both; didn't I know that that sort of thing drove up all of our insurance rates?

Surgery was not required. No bone fragments had gone into the surrounding muscle; the vertebrae had been crushed inward, toward the spinal cord. My condition simply necessitated that I stay flat on my back until the bone set itself. It was only a few weeks. My face was bandaged and my right arm in a cast. After the requisite waiting period, the orthopedist had me fitted for a body brace, shoulders to hips. No nurse stayed in the room when the salesman brought the device. He assaulted me.

My mother reluctantly offered to let me recuperate at my parents' home. I was not so foolhardy, however, as to enter that realm of violence in my newly fragile state.

After my release, I stayed with one friend or another for some weeks. I couldn't be alone just yet because I had to be rolled into the brace each morning and could not rise, turn over or sit up without it. The numerous straps and buckles were more than I could manage with my favored hand still in plaster. For the first time in my life, I had to depend on others. To learn to ask for help.

I learned, but I never learned not to hate it.

And then there was the second accident.

A fluke more absurd than the first. No point in going into details. Within a few hours, my head began to hurt abominably and I had uncontrollable nausea. My eyesight and mental focus were impaired, my head felt like it was in a vise. Years later, someone finally diagnosed this pain, which never subsided for long, as migraine.

All healing progress halted. Large doses of medicine were administered to keep me from banging my head on door frames, from pulling out my hair.

Depression set in earnest when winter came and I still had no roof and no money, despite some babysitting and stuffing of envelopes. I had my old sleeping bag and a heavy quilt in the van, but the dense fog and dampness of the L.A. rainy season and the low nighttime temperatures were hard on my body. A friend loaned me an old space heater and let an extension cord out a window. I parked in the driveway instead of the street and had enough heat to prevent illness from exposure.

I had been in school at a junior college when I was hurt and someone suggested I return and take a class just to get my mind on something.

I applied for MediCal and sat in the waiting room on a hard plastic chair for so long that the pain increased past that dreaded point where it interferes with the consciousness necessary to deal with it. And then consciousness departed altogether. When I came to, I asked what was taking so long and learned that they couldn't find my application, which had fallen behind a file cabinet. This is typical of my luck with bureaucracy.

My mother queried at frequent intervals whether I had noticed how my life had been going downhill ever since I had let her know that I didn't believe in god. She also felt that I ought to stop pretending to atheism because she had heard me say oh-god many times. One day, in frustration, I remarked that when angry

I was also known to say oh-shit but it didn't mean that I believed it had created the world. She wasn't amused but my brothers cracked up.

When my siblings visited me in the hospital, where I had to return periodically for tests and physical therapy, they formed a considerable and raucous crowd. One of the nicer nurses asked me confidentially if I would like her to limit the number of people in my room at one time. I felt at home, though, when three or four of them would arrive during one session, unaware that the others would be there. We always seem to do best when we aren't expecting each other.

Once up and around, I was to walk short distances regularly with a cane for support. It eased the difficulty in maintaining my balance, caught me when my legs buckled, and gave me something to lean on to ease my breathing. Often, acquaintances passed me by as though I were a stranger. They never noticed my face; I was just a person with a cane and they didn't know any of those. At least it worked to my advantage once, when an abusive former lover failed to recognize me.

The feds turned me down. The judge said if I could earn a good grade in school, I could work. He also said the capacity to actually support oneself was not the issue; he only had to determine that I could hold a job. If it were shown, he said, that there existed a job as night watchman in a graveyard in Kentucky, with a shack in which I could lie down as much as I wanted, this constituted proof that I could be employed.

Turns out they aren't allowed to turn you down for being a student but the appeal was denied anyway. They can't turn you down for being able to hold some hypothetical job in another part of the country, either. The appeal was still denied. I got an advocate who had never failed to obtain disability payments for a client, and lost again. I was two years older and no better. I gave up and settled into the conviction that if I tried hard enough I would get well.

Trying hard consisted mostly of staunchly maintaining a pretense that my condition was temporary and if no one treated me as disabled, especially by providing accommodation, then I wasn't disabled. A glance through my journal at the time reveals a renewed commitment to this philosophy every few months as I set, then failed to meet, one deadline after another for "getting well."

I had been feeling quite sorry for myself in the hospital one day. The doctor's report included information about the residual spinal deformity which would leave me an inch shorter and the facial scar which was hidden at the time behind an enormous bandage and had my undivided attention that day. I was weeping rather thoroughly when my visitors arrived. I explained why and my father, looking at me lying flat on my back, offered sympathetically that I didn't look any shorter to him.

I moved to Berkeley two years after the accidents. I moved all my own things, left my cane in Los Angeles, and told no one in my new home that I was disabled. I made new lesbian friends. I started school and got a part-time job.

The plan was an enormous success at first. Then, increasingly fatigued and unable to breathe, I passed out first in the campus bookstore and later in a laundromat. I would go places and return home having no idea what had occurred while I was out. On the afternoon of my oral presentation in a seminar, I realized half-way home that I had no recollection of the afternoon. (I still don't.)

Walking home during a bus strike, I stopped for a red light; it changed, I had every intention of stepping forward, but nothing happened. It was one or two changes of the signal before I could move, while leaning on my umbrella, which must have looked peculiar since it was pouring. Still, it was four years before I surrendered to the cane again. The longer I went without using it, the more frightened I felt about appearing phony by suddenly adopting it again.

I know some dykes who embrace the qualities of their disabilities on their own merits, or as a set of attributes akin to those acquired as a member of other oppressed groups. Disability culture exists but I can't live there. It would be a lie to say that I would not change my situation even if I could. Tomorrow the world could remove all barriers from the path of disabled people. The difference in my life would be negligible.

I live within the sound of constant screaming. Every cell of my body carries on a high-pitched, nerve-shattering cry all day and night. Some mornings the pain is so enormous my body cannot contain it and it looms in lowering clouds somewhere just outside of me. I awake in the eye of the hurricane, disoriented by the feeling of a surrounding pressure which is frightening but not immediately identifiable. It takes the extreme of concentration to recognize that I am, quite literally, in pain.

The sunshade on my helmet is the only reason I have a face today; also the only likely reason I am alive. I had sailed over the handlebars of the bike and cruised face first into a stone wall. I lost some memories of the past and some ability to remember in the future. For months, my vocabulary drifted and merged in and out of categories. When especially tired, I would lose all of my adverbs, or all of my abstract nouns. I would build a sentence toward a particular word and arrive at it able to grasp only that it started with a t and had three syllables.

The nightmares vanish for as much as a few years at a time, until I nearly forget their existence. Then they return without warning, shooting me screaming out of sleep several times a night, crying and streaming sweat.

One of my few clear memories of the accident is the smell of leaking gasoline. I had beaten the bike to the ground; it fell on me and fractured my wrist, dripping gas everywhere. Now I hate self-service stations with a vengeance for the smell I can't get off my hands afterwards. Although I dread running out of gas, I seldom refill until it is absolutely necessary.

Berkeley, for me, presented a new range of disability experiences. I was assailed in public when seen taking medicine, even aspirin. Offers of rosemary tea and the names of reflexologists abounded. It might have seemed a kindness if not for the inherent plea that we disabled lesbians halt our traitorous associations with western medicine.

Migraine of the magnitude I experience should not rightly be called headache. There is no correlation between it and the pain commonly experienced by nondisabled people. It is a totality of suffering which is incidentally located in the head. My body naturally braces against the torment, starting immobilizing muscle spasms along my spine. The nausea has a way of tearing open things in my low back until I cannot walk or hold myself upright.

On occasion, I must be taken to the emergency room for pain relief. The average wait for treatment is 3 to 4 hours. I have seen them treat minor rashes before they will attend to me. After all, it is only a headache.

In the throes of migraine, my being is centered on surviving it. Each time it abates, I calmly renew my plans to die — those plans which I have been formulating at the end of each migraine since I recognized their permanence in my life — because in the hours of recovery I know that I cannot want to continue with the certainty of that agony repeating regularly in my future.

I go to school part-time now, I take walks, go camping and on car trips. A few times a year, I grit my teeth and indulge in rock 'n' roll dancing — a lifelong, and formerly weekly, pleasure I will retain at any cost. I read, write, and play the piano. I have a life like most folks.

My life, though, is built around the edges of a fortress which I guard against the work, the smoke and scents, the foods and animals and lighting which can trigger migraines. I still join

political groups and try to spend the requisite number of hours sitting without taking notice of the sciatica setting my right leg on fire, the herniated disk tearing at my low back, the iron-like muscles spasming along my spine, compressing my lungs, or of the oxygen which has left my inert bloodstream almost entirely.

To say nothing of the random "hot spots," places on my back and arms which suddenly feel as though they'd been touched by a hot iron. Or the electric-shock-like feelings that pepper my rib cage at times. Or the unexplained allergies which multiply as time goes by, from foods to office supplies to perfumes to fluorescent lights. Or the way my body fails to heal any new injuries: the finger, jammed on a basketball two years ago, which still won't bend fully; the twisted ankle which remains weak; the wrist which ached after writing through a stack of carbons and was found to have developed a form of carpal-tunnel syndrome.

Poverty is largely responsible for the degree of my disability today. Had I been able to recuperate even that first year indoors, I might have escaped much of the chronic pain I suffer today. Had I had health insurance or an affluent family, I might have obtained the physical therapy and medical care which could have facilitated healing.

Three-quarters of my life was slashed away in the form of 3/4 of each day. It is not that I will live a shorter time in this life. It is that I live a much shorter time in each day. Awareness of the deprivation is renewed each morning. I am tired.

I'd like to have an end to the morality tales about everyone's friend — it must be the same lesbian — who healed herself of devastating systemic illness and structural disability through self-hypnosis or the wearing of crystals. I believe in such things, I just don't want to be badgered with them, or judged against someone else's legendary success.

Nor do I want to hear the ubiquitous miracle vitamin cure used as

a handy response from the a-b who doesn't know how to talk to a crip. As in, Oh, you're disabled and in mind-deadening pain every day? Have you tried taking calcium? It works for me after cross-country skiing. I don't want to be asked what was going on for me that year that I allowed something so traumatic to happen, or offered the empathy of able-bodied dykes who "have a bad back, too," and tend to abscond with whatever seating accommodations are available.

Also, I don't want to be regaled with lesbians' fantasies that "pain is pleasure." Pain is what disables me, sets the limits of my life, constricts my body and mind, waking and sleeping. I am deeply offended by jokes proclaiming that the misery of my life is something fun, sexy, erotic to those with the privilege to pick it up and lay it down at will. I am not amused.

And I don't want your pity. Much of the silence of the disabled springs from the near-impossibility of being treated with dignity once able-bodied others know of the indignities imposed upon us by or because of our disabilities. But knowledge is not a thing to be feared. Lesbians should be known to one another, the complexion of the present tinged by the events of the past, with no one treated as a figure of tragedy. Adversity in the past — or the present — may constitute a wound a lesbian seldom wishes to touch; but she should not be regarded as a wound with which others in the community must avoid coming into contact.

The tacit understanding seems to be that if a lesbian has never been told a story like this one — or any of the thousands which are thousands of times harder to survive and tell — nor encountered a dyke who behaves in the stereotypically doleful manner commonly assigned to those who've survived grave illness or injury, then she knows no lesbians with troubled lives. Untrue, untrue. Ask around.

Resources of Interest to Lesbians with Disabilities

Anthologies

Undiminished — Elaine Belkind, Beverly Slapin, Thomas Michael Fisher, eds. 1987.

Disabled Calligraphy — Cheryl Marie Wade, Slapin & Belkind, eds. 1988.

Close to the Truth — Cheryl Marie Wade, ed., 1989, available with comb binders & large print or audio cassette. All published by & available from: KIDS Project, 1720 Oregon St., Berkeley, CA 94703.

With the Power of Each Breath — A Disabled Women's Anthology — Susan Browne, Debra Connors, Nanci Stern, eds., 1985, Cleis Press, PO Box 8933, Pittsburgh, PA 15221.

With Wings — An Anthology of Literature by and about Women with Disabilities — Marsha Saxton & Florence Howe, eds. The Feminist Press, 1987.

Books

No Apologies — a Guide to Living with a Disability — Florence Weiner, St. Martin's Press, 1986.

No More Stares — developed by Ann Cupolo Carrillo, Katherine Corbett, Victoria Lewis, Disability Rights Education and Defense Fund, Inc., 2032 San Pablo Ave., Berkeley, CA 94702 (available on tape from them). Interviews and testimony from disabled women. Good, detailed resource guide included.

The Source Book for the Disabled — Gloria Hale, ed., Paddington Press, 1979.

Why Can't Sharon Kowalski Come Home? — Karen Thompson & Julie Andrzejewski, Spinsters/Aunt Lute, 1988 (esp. useful for power of attorney forms in appendix).

Disabled, Female and Proud!: Stories of Ten Women with Disabilities — Harilyn Rousso, Susan Gushee O'Malley, Mary Severance. Published and available from: Exceptional Parents Press, 605 Commonwealth Avenue, Boston, MA 02214, 617-536-8961.

Books Without Bias: A Guide to Evaluating Children's Literature for Handicapism — Beverly Slapin.

"Women with Disabilities" — reprinted from *off our backs: a women's news journal*, vol XI, no. 5, May 1981. Special issue on women and disability, available from: *off our backs*, 1724-20th St. NW, Washington, DC 20009.

herb woman, poetry and art by zana, includes many poems on disability. 12150 w. calle seneca, tucson, az 85743.

Periodicals

Broomstick — by, for & about women over 40 (frequent articles about disability, printed on paper & ink more accessible for environmentally ill than most): 3543 18th St, #3, San Francisco, CA 94110. Bimonthly — \$15/ indiv, \$25 instit (free to women over 40 in prison) sliding scale available.

Disability Rag — (by & for mixed audience, ongoing discussion of disability politics and culture): Box 6453, Syracuse, NY 13217. Quarterly, \$9 individual, \$15 institution.

Kaleidoscope — the international literary and fine arts magazine for women with disabilities: 326 Locust St., Akron, OH 44302.

Women with Disabilities United Newsletter — International Coalition Building, POB 323, Stuyvesant Station, NY, NY 10009.

Healthsharing: A Canadian Women's Health Quarterly (provides a critical analysis of women's health issues from a feminist perspective), 101 Niagara St. #200 A, Toronto, Ontario, Canada M5V 1C3. Quarterly, \$11/ indiv., \$19 org. and groups.

Hikané: The Capable Woman — a disabled wimmin's newsletter for lesbians and our wimmin friends, POB C9, Hillsdale NY 12529. Quarterly, \$14 indiv., \$19 instit. (free to women in prison), sliding scale available.

Mainstream: Magazine for the Able-Disabled — POB 2781, Escondido, CA 92025. 10 issues/yr, \$14.97 indiv.

Environ — A magazine for Ecologic Living, Box 2204, Ft. Collins, CO 80522. Quarterly, \$15/yr.

The Wary Canary — A News Network for "Sensitive Birds," Allergics & Environmental Health Advocates, PO Box 2204, Ft. Collins, CO 80522. Quarterly, \$20/yr.

Disabled Women's Network Canada (DAWN) (special issue of *Thriving*), 776 E. Georgia St., Vancouver, British Columbia, Canada V6A 2A3.

Hot Flash — Newsletter for Midlife & Older Women (regularly contains information about cancer & other disabilities), The National Action Forum, c/o Dr. Jane Porcino, Box 816, Stony Brook, NY 11790-0609. Quarterly, \$25/individ., \$50 org. (inquire for lower rates).

HERS Newsletter — Hysterectomy Educational Resources & Services, 422 Bryn Mawr Ave., Bala Cynwyd, PA 19004. Quarterly, \$20/yr.

Women's Tapeover Quarterly: A Digest of the Feminist Press on Tape, 66 Oakfield Road, London, N4 4LB, England.

MediSense Publishing— Information on Estrogen Therapy, Fibroid Tumors of the Uterus, Breast Cancer Treatment, Osteoporosis, PO Box 12338, Birmingham, MI 48012-2338, 313-645-1540. \$15/report (\$2 post).

Dykes, Disability & Stuff — print, cassette, Braille, PO Box 6194, Boston, MA 02114. Quarterly, \$8-20/individ., \$25/organizational, institution.

The Reactor — A Newsletter for the Environmentally Sensitive, Box 575, Corte Madera, CA 94925. Bimonthly, \$20/basic, \$10/fixed income, disability.

Womyn's Braille Press Newsletter — print, Braille, cassette, PO Box 8475, Minneapolis, MN 55408, 612-872-4352, 612-822-0549. Quarterly, \$10-25, depending on income. They also tape lesbian and feminist books and sell "Please Ignore Me, I'm On Duty" signs for guide dog harnesses.

Maize — issue on disability. Write PO box 791, Placitas, NM 87043.

Disabled Lesbian's Land

E.I.D.E.R.— Environmentally Ill Dykes Retreat, womyn only, E.I. safe, open to visitors & new members, wheelchair access in process, sign language spoken, information on tape and in print (send SASE): EIDER c/o Shemaya Mountain Laurel, PO Box 213, Kenab, UT 84741.

Arts Organizations

Wry Crips Disabled Women's Theater Arts, SF Bay Area group — first company in the US whose entire membership (writers, actors, directors, production staff and crew) are disabled women. Wry Crips is committed to inclusion, empowerment and education. The work of many Wry Crips writers is included in this and previous issues of *Sinister Wisdom*. 1613 5th St, Berkeley CA 94710. 415-525-7960 (V/TDD).

Let's Get Together: clearing-house for disabled/human/civil rights creative products. Elaine Kolb, PO Box 5294, Atlanta, GA 94710. 404-688-5828.

Disabled Artists Network — sponsors many thematic shows highlighting women visual artists. PO Box 20781, New York, NY 10025.

Organizations

Disabled and Incurably Ill for Alternatives to Animal Research, 1733 Grant St. Apt F, Berkeley, CA 94703.

The Project of Women and Disability — sponsored by the Boston Women's Health Book Collective, 617-722-7440, 800-322-2020 (both V/TDD).

Women's Cancer Resource Center — PO Box 11235, Oakland, CA 94611.

Empire Rainbow Alliance of the Deaf — c/o Fennell, 117 Christopher St. #12, NYC, NY 10014. 212-989-8241 (TTY). Gay & lesbian.

Lesbian and Gay Osteomates (and *Newsletter*) — 105 Lake Emerald Drive, #305, Oakland Park, FL 33309.

Miscellaneous

Wheelchair backpacks, standard and custom, send SASE for info to: Denise Buckbee, Run Amuk, Rt. 2, Rushford, MN 55971.

Women's History Research Center — articles and research on file on womyn and disability. 2325 Oak St., Berkeley, CA 94708.

This list was put together by Barbara Ruth, with input from the editorial staff.

Contributors' Notes ---

Caryatis Cardea is a working class lesbian separatist from an Irish Catholic/French Canadian family of nine children. Born and raised in Buffalo, NY, now studies history in Berkeley.

Jane Philomen Cleland: I am a freelance photographer living and working in the Bay Area. I am currently working on a book of photographs, maybe I'll call it *A Love For Lesbians*, maybe not, but something. I always love to talk with other lesbian photographers and artists, especially dyslexic ones — like me.

Max Hammond Dashú: I am a feminist, internationalist historian and proud to be self-educated. 15 years after the publication of my comic book *Witch Dream*, I am back to work in this art form. I love the mountains, Ethiopian music and my girlfriend.

Mandy Dee: I am white, born working class, lesbian feminist, with anarchist tendencies, bedbound with Multiple Sclerosis. I was born spastic, brought up as a disabled child, so in my mid-twenties I began to be an adult disabled from birth who also had progressive disease. Writing is a race between ability and exhaustion to get it down before I become too physically tired to think or write. I live in South London and have fought rivers of blood to get the house I now have. The situation for disabled housing is desperate.

I dream constantly about the special showcase school for the disabled I went to. The experiences that we all had as disabled people and disabled children keep me alive now. My poems have been published in *Serious Pleasures*, an anthology of lesbian erotica, and *The Common Thread*, a working class women's anthology.

Mandy died on 31st October, 1988. Her work appears here courtesy of Caroline Halliday, her literary executrix.

Barbara Noreen Dinnerstein is a cute funny Jewish butch, who happens to be fat and deaf and in recovery. She lives in San Francisco now and was born in north New Jersey in 1958.

Amy Edgington: I am a white, disabled Lesbian, forty-three-years old, living in the South. I am also an artist and a survivor of

Lesbian battering. I have written for *Common Lives/Lesbian Lives*, *Off Our Backs*, *Gay Community News*, *NCADV Voice* and an upcoming anthology from Cleis Press, *And a Deer's Ear, Eagle's Song and Bear's Grace: Relationships between Animals and Women (A Second Collection)*.

Ayofemi Stowe Folayan is the co-author of "Pursuit of Happiness" a play on the LA lesbian and gay community from 1968-88; and the performance piece "Talking About Talking: The Power to Shape the World" with Robin Podolsky, on their Black/Jewish experiences of internalized racism, anti-semitism, sexism and homophobia. Her work has appeared in *In A Different Light: An Anthology of Lesbian Writers*, and the journals *Forward Motion* and *Black/Out*. She is working on a novel while parenting an adolescent daughter.

Judy Freespirit: I live and work in Berkeley, California. Of late I am in love with Amy Rachel Ackerman, born July 7, 1989, weighing 9 lbs, 2 oz. Just call me Bubbie.

Peni Hall lives in Berkeley. She performs with Wry Crips — Disabled Women's Theater Arts. She continues to learn how to create art and do theater while dealing with the everchanging realities of chronic illness. She is currently enjoying planting a garden.

Susan Hawthorne works as an editor and reviewer. She has edited two anthologies, *Difference: Writings by Women* (1985) and *Moments of Desire: Sex and sensuality by Australian Feminist Writers* (with Jenny Pausacker, 1989). She lives in Melbourne, Australia.

Susan Hubert escaped from a college writing program years ago and is just learning to write again.

Diane Hugs — a hard person to put in any one category. With severe multiple sclerosis, she manages to stir up as many minds as she can. Being virtually bed-bound and blind would be rough on any writer, but it's coming.

Denise Jacobson: I am a disabled writer whose work has appeared in *Across the Generations*, Volume V, VII & VIII, *Mama Bear's News and Notes* and The Book Review section of *The Sunday San Francisco Chronicle*. I share my abode with my cat, Aries, my life-long partner, Neil, and my very active, beautiful two-year old, David.

Lynda Koolish is a feminist scholar teaching Afro American and American literature at San Diego State University. She lives in Berkeley half the year.

Sandra Lambert is a dyke living in Gainesville, Florida, learning to survive on SSDI.

Adrienne Lauby is a disabled white lesbian feminist who lives near the California Bay Area. She's forty years old and trying to complete her first novel. The characters in her novel are mostly lesbian punks.

Emily Levy: Poetry intimidates me: I almost never read it, and often deny writing it. My work — including poetry, if you must know — can be found in *Sinister Wisdom* 31, *Hikané* issue 1, *Maize* Spring '89, *The Courage to Heal* and *With the Power of Each Breath*. I am at work on an interracial teen-aged lesbian novel. I have had environmental illness for at least nine years. I live in coastal North California with my partner, who has always found non-toxic ways to impress me.

Jasmine Marah — disabled, dyslexic, enigmatic, eclectic, elastic, eccentric, enthusiastic, fat, forty, furious, fotomaker.

Teresa Myers is a 33-year-old blind woman of white and Cherokee ancestry. She enjoys gardening, writing, working with animals, crafts and public speaking. She lives alone with her Seeing-Eye Dog, Noser.

Shemaya Mountain Laurel is disabled, white and 31-years-old. She lives in the middle of nowhere, on EI safe Dykes' land, writes, and talks to plants. About three years ago, when her name was still Paula, she ran into an old friend who'd also gone from happily fat to unintentionally thin. Priscilla, Shemaya would love to hear from you!

Patty Overland is a disabled dyke from New York City/Brooklyn/Staten Island. She loves poetry and wheelchair basketball.

Pamela Pratt: I'm living in New York, have just finished my first novel, have been previously published in *Sinister Wisdom* and *The New York Native*.

JoAnne Rome: I am a lesbian living in Sonoma County, CA and I am very happy to be alive. This paper reflects one piece of the healing I have been doing in my life.

Barbara Ruth is a disabled lesbian. More biographical information, both literal and allegorical, can be found in the poem "Pelvic Mass Etiology."

Tee Smith: I am a fat disabled dyke who lives at the Pagoda. This, my first piece, is dedicated to Martha who continues to help me grow not only with my MS but with all elements of my life.

Naja Sorella: I'm a 37-year-old Aries (but ruled by Aquarius) Lesbian separatist, severely disabled by immune system illnesses. Stones and crystals are my preferred people to hang out with. Present favs: Black Tourmaline, Celestite, Malachite, Amethyst. Future favs: Tiger eyes, Moonstone, Topaz. Foods I love best: unsweetened carob chips, sauerkraut, fresh picked corn, roasted salted pistachio nuts (in the shell). My wonderful, deliciously round Jewish lover of six years helps make life with a devastating illness bearable. Berkeley, CA has been home for 7 years, but I hope to move before the big one hits.

Alison Ulman: Spontaneous combustion ... composting life. I build environments, but am currently looking for someone to share an environment that already exists ... waiting.

Jackie Winnow, founder of the Women's Cancer Resource Center, is a cancer activist, lesbian feminist, cat aficionada, haggler for social justice, and lover of life. A moment never goes by without the awareness of cancer and learning to adjust to an ever changing and limiting body.

zana: i'm 42, jewish, disabled with arthritis, scoliosis and allergies. i've been a part of lesbian country communities for nearly 10 years now, and dream of starting a truly accessible community of disabled dykes and our allies.

Books Received

With a Fly's Eye, Whale's Wit, and Woman's Heart, a collection celebrating relationships between animals and women, edited by Theresa Corrigan and Stephanie Hoppe, 1989, \$9.95, Cleis Press, PO Box 8933, Pittsburgh, PA 15221.

A Lesbian Love Advisor, a guide to both the romantic and practical that would make Miss Manners blush, by Celeste West, illus. by Nicole Ferentz, 1989, \$9.95, Cleis Press.

The Names of the Moons of Mars, short fiction with a "cast of characters living on the outskirts of the American Dream" by Patricia Roth Schwartz, 1989, \$8.95, New Victoria Publishers, Box 27, Norwich, VT 05055.

The Dog Collar Murders, third in the Pam Nilsen mystery series, a murder set in the complex arenas of the anti-pornography movement, by Barbara Wilson, 1989, \$8.95, The Seal Press, PO Box 13, Seattle, WA 98111.

Life, After All, experimental and visionary short stories by Québec writer Suzanne Jacob, translated by Susanna Finnell, 1979 (trans. 1989), \$9.50, Press Gang Publishers, 603 Powell Street, Vancouver, BC V6A 1H2.

Wildfire: Igniting the ShelVolution, the sequel to *Going Out of Our Minds*, proposing a new model for women's liberation, by Sonia Johnson, 1989, \$10.95, Wildfire Books, PO Box 10598, Albuquerque, NM, 87184.

Fatal Reunion, the second appearance of Detective Inspector Carol Ashton from Sydney, Australia by Claire McNab, 1989, \$8.95, The Naiad Press, PO Box 10543, Tallahassee, FL 32302.

Rice and Beans, Valerie Taylor's 13th book, is set in Tucson's barrio; 1989, \$8.95, The Naiad Press.

Heartscape, an American lesbian flees back to Portugal and discovers her attachment to the growing gay community she left behind, by Sue Gambill, 1989, \$8.95, The Naiad Press.

Keep To Me, Stranger, an inter-faith lesbian romance set in Rosenstein's department store is Sarah Aldridge's ninth novel, 1989, \$9.95, The Naiad Press.

Edgewise, Camarin Grae's fifth novel, is a spellbinder which places its protagonist in a secluded, mysterious, feminist group, dealing with death and prophecies, 1989, \$9.95, The Naiad Press.

Pleasures, erotic short stories full of mysterious lesbian strangers by Robbi Sommers, 1989, \$8.95, The Naiad Press.

Three Women, a menage á trois of sorts from Naiad's "Golden Age of Lesbian Literature," by March Hastings, 1989 (orig. pub. in 1958), \$8.95, The Naiad Press.

Chris, by Randy Salem, from "an era when love between women was a shadowy and forbidden adventure," \$8.95, 1989 (from 1959), Naiad.

A Fairer Sex View of the Martial Arts, an injunction to seek justice in training and out, in pictures and essay, by Ann Throckmorton, 1987, \$8, PO Box 151111, Columbus, OH 43215.

Confronting the Crisis in Latin America: Women Organizing for Change, critical articles by Latinas on women's roles, social policies, alternative organizations and feminism in Latin America, 1988, Isis International, Via San Saba 5, 00153 Rome, Italy and Casila 2067, Correo Central, Santiago, Chile.

Emma Goldman In Exile: from the Russian Revolution to the Spanish Civil War, a 20-year history and sequel to *Emma Goldman in America* by Alix Wexler, 1989, \$24.95 (cloth), Beacon Press, 25 Beacon St., Boston, MA 02108.

Frye Street & Environs: The Collected Works of Marita Bonner, in Beacon's Black Women Writers Series, views of Black and immigrant urban working class experiences, 1989, \$9.95, Beacon Press.

The Tribe of Dina: A Jewish Women's Anthology, the revised and expanded edition of the *Sinister Wisdom* classic #29/30, edited by Melanie Kaye/Kantrowitz and Irena Klepfisz, 1989, \$12.95, Beacon Press.

I Myself Am a Woman: Selected Writings of Ding Ling, one of 20th c. China's most important women writers, edited by Tani E. Barlow with Gary J. Bjorge, 1989, \$24.95 (cloth), Beacon Press.

Behind the Mask, a regency-style romance set in the early 19th c., by Kim Larabee, 1989, \$6.95, Alyson, 40 Plympton St., Boston, MA 02118.

Beyond Labour Issues — Women Workers in Asia — reports and papers from the conference held in October, 1987 in Hong Kong, compiled by the Committee for Asian Women, \$5, available from Women's International Resource Exchange, 475 Riverside Drive, Rm 570, NY, NY 10115.

Ancient Child — Poetry About Incest by Marcella Bryant, 1989, \$11.50pp, Plain View Press, PO Box 33311, Austin, TX 78764.

Moments of Desire — sex and sensuality by Australian feminist writers, mixed lesbian and straight writing, edited by Susan Hawthorne and Jenny Pausacker, 1989, Penguin (Australia); 1990 Viking (U.S.).

new year's eve, new, strong poetry by Gwynne Garfinkle, 1989, Typical Girls Press, 14127 Margate Street, Van Nuys, CA 91401.

Announcements and Classified Ads _____

PUBLICATIONS

HEATHER HAS TWO MOMMIES, by Leslea Newman, with illus. by Diana Souza, a picture book for ages 3 to 103 that celebrates lesbian families. To order, send \$6.95 + \$1.25 postage (50¢ add. post. per book, Mass. residents add 5% sales tax) to In Other Words Publishing, 351 Pleasant Street, Suite 233, Northampton, MA 01060. Donations welcome.

GIFT THE ONE YOU LOVE this solstice with the best lunar engagement calendar of 1990. Ethereal photographs of Blessingway Herb Farm complement elegant spiral lunar graphics. Chart fertility cycles, mood and energy cycles, dreamwork, whatever. Designed for use by a moon-gardening midwife, shows lunar phases, eclipses, passage through zodiac, planting guide, native american animal totems. 9x9, spiral bound, heavy stock with space for notes. Proceeds benefit National Woman's Health Network, Greenpeace. Reclaim an older way of seeing time and let the magical healing begin! Same day shipping, order toll-free: 1-800-372-0400, ext. 22. In Vermont, 1-800-445-5549, ext. L. Visa & Mastercard only. Or send \$13.00 post paid, to Blessingway, 321 Anawan St., Rehoboth, MA 02769. Write for free brochure of classic wise woman gifts.

TRIVIA 13 and *14*, Inspired by the 3rd International Feminist Book Fair in Montreal. #13: Memory/Transgression: Women Writing in Quebec. #14: Language/Difference: Writing in Tongues. The cultural diversity and radical experimentation of women's writing. \$10 for both: PO Box 606-A, N. Amherst, MA 01059. Subs (3 issues): \$14 dom./\$16 out of US.

Out/Inside, a Women's Newsjournal Focusing on Lesbian Prisoners. Barbara Ruth, Ed. \$6/yr, \$1.50 sample (+50¢ postage). PO Box 2821, Oakland, CA 94609.

CALLS FOR SUBMISSION

BLACK LESBIAN ANTHOLOGY seeks unpublished poetry and short fiction. Send SASE with submissions, or for more info, to: Terri Jewell, 211 W. Saginaw, #2, Lansing, MI 48933.

DREADLOCKS anthology, edited by Black Feminist writer Terri Jewell. Send SASE for info: 211 W. Saginaw, #2, Lansing, MI 48933.

WOMEN AND CANCER anthology, ed. by Judith Brady for Cleis Press, seeks submissions in all forms. Send submissions or inquiries to: Judith Brady, 62 Sussex St., SF, CA 94131. Deadline: December 30, 1989.

THE EROTIC — a special issue of *Conditions*, seeking all forms of exploration and discussion of the erotic from lesbians. Send SASE with submissions or for more information: *Conditions*, Box 159046, Brooklyn, NY 11215. Deadline: February 1, 1990.

LESBIAN BEDTIME STORIES VOL. II — unpublished short stories. Send ms. and queries with SASE to: Tough Dove Books, Box 528, Little River, CA 95456. Deadline: April 1990.

WOMEN'S HITCHHIKING STORIES: for development into a performance piece. Deadline: January 1990. Send stories or taped narratives to Carolyn Gage, 272 Orange St., Ashland, OR 97520. Deadline: Jan. 1990.

FANTASY/SCIENCE FICTION by and about women, for a Crossing Press anthology, Susanna J. Sturgis, ed. Send ms. & queries with SASE to: PO Box 39, W. Tisbury, MA 02575. Deadline: January 15, 1990.

WOMEN'S RECOVERY STORIES for anthology to be published by Crossing Press. Send ms. & queries with SASE to: Susanna J. Sturgis, PO Box 39, W. Tisbury, MA 02575. Deadline: February 15, 1990.

WOMEN'S STORIES ON THE DEATHS OF THEIR MOTHERS for an anthology. Send ms. & queries with SASE to: Helen Vozenilek, PO Box 18, Berkeley, CA 94701. Deadline: December 31, 1989.

LESBIAN AND GAY TEACHERS AND STUDENTS: THE POLITICS OF THE CLASSROOM, work in all forms addressing rights, homophobia, gay parents, peer & community relations, gay students, bibliography, more — queries and ms. to HerBooks, PO Box 7467, Santa Cruz, CA 95061. Deadline: December 15, 1989.

HEALING FROM INCEST THROUGH ART — anthology of works in all media, to be published by Seal Press. Send 6-8 pp prose or poetry, 4-6 slides, with SASE to: Louise Wischild, 606 19th E., Seattle, WA 98112

THE LESBIAN AND GAY WEDDING BOOK seeks photos, vows and 500-1000 words on the process. For submissions or more info: WIM Publications, Dr. SDiane Bogus, 3601 Crowell Rd. #100, Turlock, CA 95380.

LA BELLA FIGURA — a literary journal for Italian-American women, with a special welcome for lesbians. Send SASE for guidelines and subscription info to Rose Romano, PO Box 411223, SF, CA 94141-1223.

FATHERS AND DAUGHTERS — a prose anthology from Crossing Press. Send queries and ms. to editor: Irene Zahava, 307 W. State St., Ithaca NY 14850. Deadline: February 1, 1990.

LESBIAN HUMOR, any and all forms, for a Crossing Press anthology. Send queries and ms. with SASE to: Irene Zahava, ed., 307 W. State St., Ithaca, NY 14850. Deadline: February 1, 1990.

CONTEST

SPINSTERS/AUNT LUTE LESBIAN LONG FICTION contest offers \$2,000 prize for novel-length, well-crafted fiction focusing on the lives of lesbians. Ms. accepted January 2-February 28, 1990. Write for rules: PO Box 410687, SF, CA 94141.

CONFERENCES

NATIONAL LESBIAN CONFERENCE, April 1991 in Atlanta, Georgia. Local organizing and national meetings are happening around the U.S. now. For more info, write: PO Box 3057, Albany, NY 12203.

LESBIAN ARTISTS' EXHIBITION and WOMEN'S CAUCUS FOR ART CONFERENCE, NYC, Feb. 1990. For info, send SASE to Myriam Fougere, 118 Fort Green Place, Brooklyn, NY 11217.

IV INTERNATIONAL FEMINIST BOOKFAIR, Barcelona, Spain, June 19-23, 1990. Exhibits, workshops, discussions in Catalan, Spanish, English and French. For information, write IV International Feminist Bookfair, València, 302/08009 Barcelona, Spain.

ASSOCIATION FOR WOMEN IN PSYCHOLOGY 1990 National Conference: "Feminist Psychology...Reclaiming Liberation," March 8-11, Tempe, Arizona. Activist, accessible orientation. 1990 Conference Collective, 110 W. Geneva Drive, Tempe, AZ 85282.

7th ANNUAL NATIONAL GRADUATE WOMEN'S STUDIES CONFERENCE: "Women in Scholarship...There Are No Limits." U. of Penn., Philadelphia, Feb. 23-25, 1990. Info: c/o Women's Studies Program, 106 Logan Hall, 249 S. 36th St., U. of Penn., Philadelphia, PA 19104-6304.

OUTWRITE '90. the first National Lesbian & Gay Writers Conference, March 3-4, 1990, in SF. For info, write OutWrite c/o *OutLook*, PO Box 460430, SF, CA 94146-0430.

GENERAL

GOODMAN ANTI-PORN DEFENSE FUND seeks contributions to fight felony charges from anti-pornography action in Amherst, MA in Jan., 1989. Donations payable to: H. Horak/(Goodman Anti-Porn Defense), PO Box 953, Northampton, MA 01061, or write for more info.

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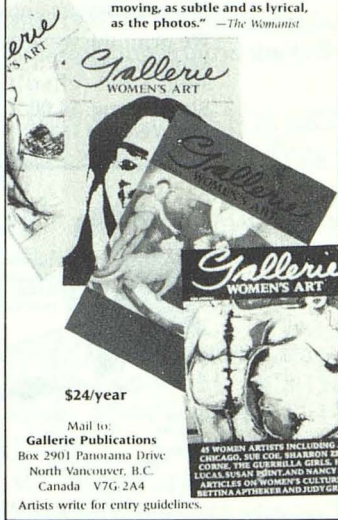
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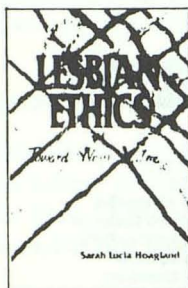


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We are particularly interested in work that reflects the diversity of our experiences: as women of color, ethnic women, Third World, Jewish, old, young, working class, poor, disabled, fat. We will not print anything that is oppressive or demeaning to lesbians or women, or which perpetuates negative stereotypes. We do intend to keep an open and critical dialogue on all the issues that affect our work, joy and survival. See p.9 for details on upcoming issues. The themes are intended as guidelines, not as rigid categories. If you have work that doesn't fit an upcoming theme, but belongs in *Sinister Wisdom*, don't hesitate to submit it.

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—Lynda Koolish
