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### Living “Anyway:” Stories of Access

Elana Dykewomon<sup>a</sup>

<sup>a</sup> Independent Cultural Worker

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## Living “Anyway:” Stories of Access

ELANA DYKEWOMON

*Independent Cultural Worker*

*Elana Dykewomon’s 1974 novel, Riverfinger Women, was among the first lesbian books with a “happy ending.” Her seven books of fiction and poetry include the Lambda Award winner Beyond the Pale (now an audio and e-book) and Lambda nominee, Risk. She was an editor of the lesbian-feminist journal, Sinister Wisdom, for eight years. Her literary work foregrounds the lesbian heroic as integral to women’s communities. As a social justice activist, she has organized and participated in anti-war, anti-racist, anti-classist, fat and disability rights work since the 1970s. She is now working with Old Lesbians Organizing for Change. She is happy to live embedded in dyke community as a lesbian radical committed to a loving justice. While she suffered psychiatric abuse at 13 (and acknowledges long-term adaptive behavior on that account), she has not experienced disabling mental illness since. Her primary disabilities are mobility impairment through severe, progressive arthritis and constant low-to-powerful pain, sometimes diagnosed as fibromyalgia. Her acute illnesses include pancreatitis and a rare-in-adults kidney disease currently in remission.*

**KEYWORDS** *Elana Dykewomon, lesbian leaders, lesbians and medical treatment, lesbians coping with disability, lesbian friendship networks, lesbian support systems, best medical practices, fat studies, old lesbians, friendship and death, kidney disease, pancreatitis, interdependency*

The topic of how leaders cope with disability/illness is fraught, layered with questions. What is leadership? What is disability? Which one counts as the one I should write about, will matter the most to readers? What *do* readers want? Not a complaint, certainly. And, at this point in my life, I have little to complain about, much to be thankful for: good friendship networks, good

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Address correspondence to Elana Dykewomon, E-mail: [dykewomon@yahoo.com](mailto:dykewomon@yahoo.com); [www.dykewomon.org](http://www.dykewomon.org)

health insurance, resources to help me through medical and social hurdles. I am grateful for these things and extremely aware of how rare they are for most of the world's population. We have so much work to do. My hope is that this article is part of it.

## LEADERSHIP

I have spent nearly all my adult life within lesbian and women's communities and movements. I have a long list of accomplishments—organizations I have helped found, readings and conferences I have organized. But asked to write about my experiences as a "leader," I got flustered. Leader?

Okay. I will accept this label, although it's always been hard. These are the reasons why it's hard for me, personally, to accept being called a leader, some of which will likely resonate with other leaders, who also have their own lists:

- Leader implies: hierarchy, an assumption of power and control. And it implies duality—leaders and followers are perceived as fixed roles. The fact is that leadership is (or should be) dynamic, fluid, situational. I acknowledge that leaders are important: people who express visions and ways to achieve them. Leaders are women who do not accept the state of things as they are and try to forge new paths; who speak up and follow through. Yes, I have done that. And sometimes I have listened, done my part, held my picket sign, following others' leadership. But when something needs to be done and I know it, or I start to question assumptions—I gird my loins and speak.
- I am a woman, and have all the internalized emotional structures of women: wanting to take care of others, not wanting to take up too much space, not thinking I have an effect beyond the personal, if that. Internalized misogyny is powerful and deep. Sometimes leading is simply acknowledging how difficult it is to be a woman taking charge—right?
- I am fat and trained to fear that I take up too much space, that no one takes fat women seriously. See above for internalized self-doubt, self-effacement.
- I am a white-skinned woman with middle-class privilege, and part of how those privileges work is through denying power. When I do not recognize the power my privileges give me, I do not have to think about how privilege affects my politics, projects, and relationships. And it does. So part of my work in being a leader is copping to my part in institutional racism and classism. To change that, I have to understand and claim my leadership.
- I am a survivor of childhood psychiatric abuse, having been locked up at 13 for over a year after several suicide attempts caused by my realization that I was a "homosexual" and the world held no place for me (it was 1963

and we lived in Puerto Rico, making it impossible to run away effectively). One of the strongest messages I got in mental institutions was: do not stand out. Fit in. You do not want to get locked up again, do you?

- I am old. This is a complicated barrier to leadership, except among other old women. Young women tend to “thank you for what you’ve done,” and otherwise not see you as part of their ongoing movement. Since the women’s and lesbian movements have never had lasting institutional places for intergenerational organization to happen, for historical memory to be transmitted as part of theoretical development, women my age and older often find ourselves reduced to media myths we do not recognize, and pitted, before we speak, against women coming into the first flush of organizing. And sometimes we become oppositional without listening, too.
- I am disabled. My disabilities vary in intensity, and if I compare myself to others, I often feel like my disabilities are “not so bad.” But comparison is a trap, about which another whole article could be written. Having disabilities—not being able to walk well or far, to “keep up” with my peers, having constant, low-to-severe-level pain, has often made me feel—like I should not be trying to take part, that I was holding others back. This was stronger when I was young, when participating in groups meant being able to sleep on the ground, sit on floors or march in protests for hours.

### LIVING “ANYWAY”

I detailed all those things because the question is so complicated. Is it that way for every disabled lesbian leader? Yes, I think so, in some form. It’s different to grow up able-bodied, of normative size, without psychiatric “history,” and become disabled or critically ill in later life. When you take the stage at the moment of your greatest power or strongest conviction, you do not have to worry about getting up on it—and that’s a tremendous difference.

I am stopped here, remembering my friend Gloria Anzaldúa, who overcame tremendous barriers to create revolutions in thinking with *This Bridge Called My Back* and *Borderlands/La Frontera*. She was disabled by, and died way too young from, diabetes. While she did not have physical trouble getting up on a stage, finding herself “on stage” was a challenge to the barriers that racism and classism had presented all her life, and a challenge she often met by standing in front of the podium, at audience level. There she said: see me. See my small Chicana body, a body that was not supposed to be here, taking your time and space. And then she would proceed.

She opened her heart and her life; laying bare pain, fear and her “wild tongue,” she made openings for many people, created courage by example. Courage, at its root, is heart. To take heart, to have an open heart, to expose your heart: all these take courage.

It's hard to have courage about your own pain, your experience of pain. Pain is a citadel guarded by privacy, and the impulse to privacy takes its task seriously. I can work for whatever I think is just, and analyze the intersectionality of oppressions, organizing and writing. But that core internal psychic space where I have to take care of myself? Leave me alone there. That space is vulnerable. What use are my struggles with my body to you?

That's the question, is it not? Yet every time I expose some part of those struggles, it resonates and helps other women find their voices. I value the voices of women. So this is the story of my body, my body politic, at least part of the story, the story I can write today:

I have always experienced being differently bodied than my peers. Although I do not remember this, apparently I was born with some kind of leg "deformity" that involved my parents agreeing to putting leg braces on me as a toddler. I have always had varying degrees of pain walking, which caused me some ridicule as a child ("quit whining!") and as a young adult who "could not keep up" with able-bodied peers. When I was eight or nine, I used to create fantasy castles out of books or sand, filling them with marble or seashell "people," who were fighting some injustice. The hero was always a lame prince, whose bravery was taken as an inspiration, and who was loved "anyway."

And I have always been fat—early genetic fat increased first by dieting<sup>1</sup> and then in response to psychotropic drugs in early adolescence. Fat and disability are not the same things, and many fat folks are in excellent health. My own mobility problems, have, to some degree, been compounded (not caused) by fatness (speeding up arthritic degeneration in my knees), but my overall health has benefitted from giving up "dieting" in my early 30s. The struggle is finding knowledgeable or, at least, willing-to-be-educated, health professionals who do not attribute every physical problem to being fat.<sup>2</sup> And because of massive anti-fat propaganda, many do not credit fat women as organizers, artists or thinkers. I participate to the best of my ability "anyway."

Those psychotropic drugs I got when I was locked up had side effects. I believe they did long-term damage to my nervous system, impossible to know specifically. Often I shrug; "it was a long time ago" and "I overcame that" but it has shaped my life dramatically. My mother sometimes marvels that I have done so well in life, considering my "early illness." She thinks, as I expect many in my extended family think, that I have been successful "anyway."

I had up-all-night-cursing pain from carpal tunnel in my twenties and at various other points; by the time I was 30, various chronic pain syndromes were diagnosed in various ways. They are sometimes mild but increase with certain kinds of activity/over-exercise and now with age. At the same time, I developed osteo-arthritis, which appears to be hereditary, and found standing for hours at the day job I had in my early 30s, which was being a printer, extremely painful (I kept doing that work for about five years,

“anyway”). So far I have had one knee and one shoulder replaced; one ankle and the other knee need to be, but I am trying to space that out.

### WHAT PAIN MAY GIVE

Long-term “conditions” inspire a range of adaptive behaviors. Calling them conditions is not right, though. My body is my body, not a condition. I do my best to inhabit it consciously, compassionately. When I am in pain, I am good at distracting myself. Like my mother (or because of modeling my mother’s behavior), I have a high tolerance for pain and a high level of endurance. I have often called on some mysterious inner reserve to see me through physically challenging situations.

Those aspects of my body, of living in a body full of *ongoing* challenges, shape my political persona, but are things I have mostly not asked for “help” with, although I have relied on the caring and sensitivity of friends and lovers as I revealed myself to them. I have been blessed (a word I rarely use) in having many thoughtful, generous-of-mind-and-spirit friends, many of whom have become my family over the last forty years. Some of them I can count on to wipe my ass after shoulder surgery when I could not use my right arm; some I can go to when I experience fat-hatred in the world and need a sounding board.

There will always be moments when you want/need someone to come through for you, to be there, to take care of you—and no one is. This is probably one of the hardest experiences to react to, to form a reaction to. It’s important not to harden in that place, to say—okay, it’s just me, screw you all. It’s important to keep asking, to keep relying on the people close to you. Yes, we are all ultimately alone, but we are also part of each other, bound to each other’s well-being. No one can bear the pain of physical distress for anyone else, but they can listen, respond to requests for help, bring tea. It’s important to stay open.

As they are for anyone, the intimate parts of critical illness are—intimate, vulnerable. Being a leader is not a fixed identity—it’s what you do when you feel a measure of control; if you are vulnerable as a leader, it’s because of mistakes you make, ways that you operate out of assumptions that hurt others. You do not *be* a leader in moments of extreme physical need. You be then a human animal, frightened of your pain, trying to hold it together, leaning as much as you can on the intimate folks you trust.

But pain and fear teach you things you bring back to your wider community life. They taught me compassion, patience, fortitude—an old fashioned word that means resilience, staying power, determination. Leaders need these things.

The lessons of relying on others become clearer in crises. I have also had a couple acute bouts of life-threatening illness. The first was pancreatitis,

which came close to killing me in 2001, but was remedied by removing my gall bladder.<sup>3</sup> I developed atrial fibrillation and had to be stabilized for days before they could operate. At that particular moment in time, my partner, Susan, had been talking about moving to Vancouver—it was beautiful, we had been there several times because I had a wonderful Canadian lesbian publisher,<sup>4</sup> and we admired the Vancouver lesbian community, liked the women we met and stayed with. But when I was in the emergency room in Berkeley, my best friend Dolphin showed up, with another friend—then many women converged and were present for Susan and me in that moment.

When you are very ill you often do not want a lot of folks around. I was delighted that so many showed up, and just as glad that Susan or Dolphin were able to shepherd folks into the hall or waiting room after a few minutes. The immediate support floored Susan, and she realized how important it was to stay in the Bay Area, within our friendship networks.

Several years after the pancreatitis, I developed an uncommon kidney disease called “minimal change disease,”<sup>5</sup> which was misdiagnosed for four months as inflammatory breast cancer, a particularly fatal kind with a life expectancy of 18 months after diagnosis. After three breast biopsies and one kidney biopsy, I was treated with an intense course of steroids over two and a half years (along with acupuncture and homeopathy), and finally went into complete, hopefully permanent, remission (which requires minor dietary restrictions).

Believing I had a specific, life-ending cancer was what taught me the most about death, and my importance in other people’s lives. Death has always been a worried place in my mind; if my mind were a stone, the surface with the word “death” inscribed would be worn so smooth by now you could barely make out the letters. But when, as an adult, in the middle of my community, death seemed imminent, I stopped fearing it, stopped having anxiety about what happens to you when you are no longer thinking, dreaming, making yourself up every day. I “got over myself” and understood, as I had never understood before, how connected I am to the women of my community; the grief my passing would bring to those most intimate in my life; the ripple effect it would have within the lifespans of those who knew me.

The hardest thing to bear was the experience of loss I could feel in those around me. I believe, if the diagnosis had turned out to be true, at some point I would have known viscerally (as opposed to intellectually) that separation is the contract we make with love, that the loss of those we care about is part of the life we have with them. But I had not gotten there yet when, after four months of thinking I was about to die, the doctors said, no, inflammatory breast cancer is not what this is, it has to be something else.

And oddly, six or so months into dealing with the much more treatable kidney disease, my old, personal anxiety about dying returned; now I could

raise an eyebrow at it, though. You cannot scare me, death. I know I will be ready when the time comes.

## BONDING NETWORKS

When you were in your twenties—remember? Did you not come to realize that one of the ways to make friends was to need them? To need someone in the middle of the night because your car broke down or you could not find any place to sleep or your heart had been broken? To need the woman in bed next to you to hear your private fear and longing?

To confess need to a sympathetic ear, that became the glue. On our first rough maps of friendship, people are bound to each other by what, on the surface, we call common cause or attraction. But underneath attraction or recognition is a vast network of pain, when we find ourselves stuck in the muck of personal circumstance and need witness.

Margaret Atwood has a terrific poem, "Siren Song,"<sup>6</sup> which posits that the irresistible refrain is "a cry for help: Help me! / Only you, only you can, you are unique. . ." In Atwood's poem, the point is that our egos, flattered, fall for the Siren's duplicity in asking for help, and, drawing close, are devoured. That happens. Any of us can be trapped by our desire to be needed; and occasionally people will play us.

But more often the call for help is hard to make, and sincere. Answering it gives us (at least) two things: a sense of our own strength/ability to cope with another's adversity and a bond. We are happy to be bonded together, and then we struggle with what our reliance on each other means; that struggle is different for each of us.

As people face disability, they often talk about the fear of losing independence. Senior housing has a hierarchy of need built into its nomenclature: independent living, assisted living, nursing home. When we get help, we fear we are giving up our independence, giving in to some shameful need.

How does need get paired with shame? How does knowing we are interdependent morph into anxiety when we actually call on each other? No doubt about it, I was ashamed when I needed help wiping myself, pulling up my pants. The shame was mine—the women I turned to at that point were as loving, gentle, and helpful as anyone could wish. I accepted their help, but was really glad when I did not need it anymore.

But I still need their help. I need them to need me when they are sick or have an emergency; I need to know I have friends I can call at 2 a.m. if I need to go to the emergency room.

I am not sure being a leader has anything to do with the need for these things, except to acknowledge them, to encourage and illuminate our interdependence. The qualities that make you appreciated in your community may lead women to volunteer their help, though. What happens



to women without friends, or without friends who can still respond at 2 a.m., or 4 in the afternoon? This is the fear worse than fear of death: to have no bonds to others you can rely on, who can rely on you.

Without that, women are consigned to Medicare nursing facilities, or private nursing homes if they have the means (which the vast majority of women do not). When we are in our thirties or forties, this seems far away, something we will deal with later, when we need to. Women in my generation and the ones before me are dealing with this now. We are having some organizational success through OLOC (Old Lesbians Organizing for Change) and SAGE (Service & Advocacy for GLBT Elders), but we are a long, long way from even beginning to provide affordable care, community housing, and intergenerational support networks for old and disabled lesbians.

We create community not out of fear of what will happen to us, but out of excitement, desire to transform the world into a safe and just place for everyone. Can we keep that desire as we face the challenges of disability and age?

## COMMUNITY

Because I am a writer, my words went out into the world before my body did, and women who never met or saw me supported my work, and (usually) remained supportive once they did meet me. But I was already constructing the persona of someone who moved through the world “anyway,” who would get naked at the swimming hole with all the rest of the women, who refused to let others’ reactions to my fat, slow, butch body stop me.

Living “anyway,” despite all the barriers set in your way, is a necessary personal response—especially if you have ambitions, want to accomplish things. But it is also a symptom of the “individual solution” that our hierarchic cultures encourage. That is, it’s on you to adapt, to overcome, to find out how to do what you want; it’s on you to join the crowd, to not stand out, to not make a fuss or draw attention to yourself. And once you have achieved your own solution, that’s it. You have got yours—everyone else can fend for themselves like you did.

When I was in Belgrade in 2012 to do readings as part of “lesbian spring” in Serbia, I noticed that not only was the city full of barriers—no curb cuts, few accessible bathrooms, no consciousness about access in the radical community center where I read—but disabled people were nowhere to be seen. I asked one of my translators why that was, and what happened to all the people who had recently become disabled due to the war. She told me the government gives them pensions and wants them not to be visible—not out on the streets as a reminder of what happened in Serbia.

Awhile back, I gave a lecture and readings at a university in the Midwest. The partner of the lesbian who invited me had a progressive disability, and

had been using an electric chair for a number of years. My host told me how she and her partner were excited when a friend announced plans to remodel—they expected that a new space would become available to them, that they would be able to participate in their friendship network more fully. The remodeling women did not consider accessibility as part of the job, and the house remained out of bounds.

Once<sup>7</sup> at a large lesbian conference in Atlanta, a disabled dyke was invited to give a speech from the main stage, and told to go around to the loading docks where the wheelchair accessible entrance to the stage was. That entrance was locked, and no one ever came to unlock it.

Many years ago (1982!) I was going around the country giving readings in women's spaces, many of which were inaccessible (in basements and lofts because they were cheaper). I asked organizers to consider alternative spaces and ramps, to work harder to develop sustaining resources for access, and requested that the events be posted as scent-free in consideration of environmental disabilities, as well as that no diet drinks be sold at the venues. Damn, did I get flak from (all of) that—if not from the organizers, then from members of the community. Stop making these PC demands on us! was the general response. Unfortunately, while many inroads have been made and many organizations give at least lip-service to accessibility, many still find it an onerous burden. Many organizations meet the demands of the disabled community by saying: when we have the money; when we can; the benefit was at a private house, we cannot dictate to them; disabled people are not coming.

Well. Of course if we are not welcome, why should we come? This is not exactly an article on disability rights, but why not? Being a community leader, whether or not I ever had access issues myself, means developing an awareness and consciousness of them. And yes, access means I, too, can come into your space. Do you not want me?

Accessibility has a different narrative than making your life "anyway." Social structures would be set up with as few barriers as people can imagine; organizations would respond positively when someone points out a barrier that has not been considered yet. Individuals would not have to develop defensive postures in spite of other people's desires to have them disappear or blend into the background. Everyone would be welcome.

Not because it's "PC" but because we need each other, we need every perspective; and we need to ensure that we respect each other's dignity, each other's bodies, as we wish our own to be respected. Try to imagine an activist universe in which every venue is wheelchair accessible, signed, scent free; where no one supports the diet industry, and if t-shirts are sold, they come in sizes up to 6x; conferences where scooters, hearing devices, and captioning are provided for attendees.

Us leaders have to think harder, think together, on how to keep providing access for those who do not have friendship networks that will support

them, whose friendship networks have been decimated by poverty, illness, disability, and death.

The trouble with writing essays at this point in life is that they run together. There is only one essay, after all, and its point is: We are all in this together. Keep figuring out what that means. Then act.

## NOTES

1. Most folks do not want to believe this, but yes, dieting makes you fat, or fatter: the body interprets dieting as starvation and metabolism slows. Consider the empirical evidence of how many dieters report gaining more weight over a 5-year period.

2. The conflation of fat and disability in most people's minds is a barrier to both health (especially in medical settings and exercise facilities where fat people are often stigmatized or patronized) and to social participation, where many people project an attitude that fat folks have "chosen" to have a "disease."

3. Do not take severe stomach pain lightly—people frequently die from pancreatitis, an inflammation often caused by gall stones.

4. Press Gang, now gone and deeply missed.

5. The "minimal" refers to the fact that it's diagnosed with a very high powered microscope, which can see cellular changes that result in dramatic, severe symptoms—the experience is anything but "minimal."

6. Margaret Atwood, *Selected Poems, 1965–1975*, Houghton Mifflin, Oxford, 1976.

7. But I do not want you to think this happened "once." Women who use chairs or have other mobility problems experience this frequently. This year. This week. Today.