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In All the Rooms of the Yellow House (poems)

Waist-High in the World

A LIFE AMONG THE NONDISABLED

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BEACON PRESS
BOSTON

BEACON PRESS
25 Beacon Street
Boston, Massachusetts 02108-2892
www.beacon.org

BEACON PRESS BOOKS
are published under the auspices of
the Unitarian Universalist Association of Congregations.

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Printed in the United States of America

14 13 12 11 10 14 13 12 11 10

Text design by Anne Chalmers
Composition by Wilsted & Taylor

Library of Congress Cataloging-in-Publication Data
can be found on page 214.

For
ANDREW HRYCINA
enabler par excellence

Young and Disabled

LUNCHTIME. Your favorite café. Blinking away the dust and glare of the street, your gaze falls on a woman at the corner table. Her dark hair swings softly against cheeks as flawless as porcelain, and her chin rests on the slender fingers of one hand. In her beige silk blouse and ivory linen suit, she has the crisp appearance of someone who holds a powerful job and does it well. She leans forward to say something to the man across from her, and when he throws his head back with a deep laugh, her eyes sparkle.

Yourself, you're having a bad-hair day, and a zing up your calf tells you you're going to have to dash into the drugstore for a new pair of pantyhose before returning to your office, where the world's most boring report lies on your desk, still only half read. You stayed awake half the night worrying whether your boyfriend will take

the job he's been offered in Denver, and now your brain feels as soggy as a fallen log under a thick layer of moss. But your stomach is rumbling, so you head for a table in the back.

As you pass the woman, you see with a start that she's sitting in a wheelchair. "Oh, the poor thing!" you think. "How courageous she is to fix herself up and get out of the house on a day as hot as this. And what a thoughtful man—her brother, it must be—treating her to lunch to cheer her up." In an instant, your mossy brain has dredged up an entirely new creature. The person you first noticed—the glamorous career woman enjoying a flirtation over lunch—is no more real, of course, than this pitiful invalid putting a brave face on her misery. Both are projections of your own imagination—your desires, your dreads. But because you admire the first, you're more likely to want to know her; the second, because she makes you uneasy, will remain a stranger.

The "you" I refer to is as much my young self as she is anyone else. In those days, I knew almost no one with a disability. When I was a child, one of my uncles had become partially paralyzed by polio, but he moved to Florida and I seldom saw him after that. Although two of my college classmates had been disabled, one quite severely, and I remember watching in wonder as she maneuvered her crutches over paths made treacherous by the New England winter, I didn't happen to know—or did I avoid knowing?—either of them well. Those were the days before buildings were ramped, elevators installed, and bathrooms modified for accessibility, and I

can't imagine how complicated and exhausting and downright dangerous their lives must have been. No wonder relatively few disabled people ventured out into the world.

Then I became one of them. When my neurologist diagnosed my multiple sclerosis, he told me that I had a "normal" life expectancy. But, he didn't have to tell me, I wouldn't have a "normal" life, not the one I had prepared myself to live. I was going to be "disabled," more severely as time went on, and I had no idea how to live such a life. Could I go on teaching, and if so, would anybody want to hire me? Would my husband still find me sexually attractive, and could he accept my increasing need for help? Would my children resent having a mother who couldn't do everything that other mothers could? How would I survive if they all abandoned me? Did I even want to live to find out the answers to these questions?

As such questions suggest, I subscribed to the major social myths about the "disabled woman": that she lacks the health or competence to hold a job; that no man could want her or care for her, either physically or emotionally; that disability can only damage, never enhance, friendships and family relationships; that suicide is an understandable, even a rational, response to physical impairment, rather than the symptom of depression it is known to be in nondisabled people. Above all, I felt permanently exiled from "normality." Whether imposed by self or society, this outsider status—and not the disability itself—constitutes the most daunting barrier for most people with physical impair-

ments, because it, even more than flights of steps or elevators without braille, prevents them from participating fully in the ordinary world, where most of life's satisfactions dwell.

Gradually, I stopped thinking of myself as an outcast, and over the years I have watched the social barriers crumbling as well. As technological advances permit disabled people to travel, study, and work, and as the media incorporate their pictures and stories into articles, advertising, television programs, and films, their presence becomes more familiar and less frightening. Many of them are eager to promote this process, as *Glamour* magazine discovered by asking readers with disabilities to write about their histories and the effects that their physical circumstances have had on their work, their friendships, and their love lives. Letters and faxes flooded in from several hundred women (and a handful of men), ranging in age from sixteen to eighty-five but most in their twenties and thirties, who were "intrigued," "excited," and "thrilled" at being asked to emerge from the shadows. Having the chance to collate these for an article I wrote for the magazine, I became charmed by the frankness, grit, and good humor these women displayed.

The challenge in compressing their replies—many of them covering several closely typed or handwritten pages—lay in fairly representing their diversity. Their disabilities varied so widely that it was difficult—even deceptive—to generalize about such women, who may have less in common with each other than they do with some nondisabled women and who may even be made

uneasy by women with disabilities different from their own. As Peggy Merriman, who was diagnosed with multiple sclerosis when she was nineteen, protested, "The general public seems to have an easier time (or simply unconsciously prefers) dealing with people with disabilities by lumping us all together and assuming that we all have the same problems and, what is worse, that *all* we deal with or have in our life is our disability." But defining someone solely in terms of what she cannot do tends to distort her life: "I feel I have been neatly tucked into a category with no room to move," wrote twenty-one-year-old Naomi Passman, whose legs were paralyzed in infancy by a spinal tumor, but "the last thing I need are limits!" I hope that, as these women speak, "disability" will emerge as one element of their complicated personalities and not as a confining category.

Nevertheless, as every woman who wrote to *Glamour* has long since found out, breaking free of a category doesn't abolish the realities of the disability itself, which may include weakness, fatigue, deformity, physical pain, bouts of illness, and reliance on technical assistance like crutches, wheelchairs, or hearing aids. In a society that equates "vitality" and "beauty" with physical soundness, a disabled woman must come to terms with serious shortcomings often earlier and even more urgently than others. In this process, these women have learned from experience what many their age understand only intellectually, that life itself is imperfect: the best qualified person doesn't always get the job, the most loving heart doesn't always find a mate. Although

a few responded to such knowledge with bitterness or apathy, most seemed to take it as a challenge. Their lives might not be "perfect" by conventional social standards, but they were determined to live productively and passionately anyway.

Those who were disabled from birth, by conditions like spina bifida and cerebral palsy, had to cope with being "different" during the time when social conformity seems most compelling. For many of them, childhood was anything but carefree, since they often faced both painful medical treatments and the taunts of "normal" schoolmates. Their reactions to their situations often diverged, however, as revealed by the responses of two women with osteogenesis imperfecta, a genetic disorder that causes bones to fracture very easily. "My parents were somewhat over-protective, which is highly understandable," wrote Felicia Wells Williams, a young African American woman who was born with several ribs and both arms already broken. "However, some of their apprehensiveness about my 'fragile' condition rubbed off on me. As a young child, I was told to be careful and think of the consequences of my actions. So I became fearful of certain things—heights, falling down stairs, etc. I spent a lot of my childhood being a spectator—watching others have fun." Konie Gardner, with the same diagnosis, recalled that her parents assigned her Saturday chores just like her five brothers and sisters and gave her every opportunity to try whatever she wanted. "I was always an accepted kid in the neighborhood, too, and even though I could not physically par-

ticipate in many of the games, etc., I was an enthusiastic spectator and never felt left out by anyone." Whereas one felt she was missing the fun, the other had fun just watching.

Many received the kind of encouragement Kim Silvey reported: born with dislocated hips that required ten operations while she was growing up, Kim "wasn't one to hide and not be seen by anybody," thanks to her parents, who "instilled in me confidence and the belief that I could do anything I wanted, and that's the attitude I grew up with and the one I still hold today." She added, "It would have been so easy for them to coddle me and try to keep me out of the 'evil eye' of the world and to try to shelter me from the pain others could inflict upon me. I credit my being who I am today to my parents' unwillingness to hide me because I didn't fit the 'normal' mold."

Even those with supportive parents often found other children cruel. "With a toe first walking style, slurred speech and nearly no fine motor coordination, I was not what anyone considered popular," recalled Barbara McGuire, thirty-four, born with cerebral palsy and educated in regular classes. "I was the first to get 'cooties' (call me if you don't remember this social disease of elementary school kids); the last to get rid of them; the first to get teased; the last to get picked in gym." From early on, "boys were terribly mean," and by junior high school girls were, too, "to impress the boys." Only after entering an all-girls' high school did she begin to make lifelong friends.

The struggle for approval from nondisabled peers can

have humorous consequences, as Juli Delzer, born with a 60 percent hearing loss in both ears, revealed. As a child, "I was so painfully shy about my deafness that it was embarrassing to let people know that I couldn't hear. I came up with what I call 'deaf answers.' If someone asked me a question that I didn't hear, I would answer with 'yes,' 'no,' or 'I don't know,' hoping that I had covered the bases and given an appropriate answer. This didn't work so well when I moved to a new school. In gym class one day, someone turned around to ask, 'What's your name?' To which I answered, 'I don't know.'" Now, planning to do small animal husbandry in the Peace Corps before she begins veterinary school, Juli has grown self-assured enough to give up these "deaf answers," but still, she wrote, "I am very aware of my handicap in relationships with men. They can't whisper sweet nothings in my ear because I would be forced to look at them and whisper back, 'What?'"

In addition to a sense of humor, pride did much to carry these women through their awkward childhood years. "On the day I received my first hearing aid, when I was nine years old, my doctor assured me my long hair would easily hide it," wrote Madeline Cohen, a student at Stanford Law School who was also born deaf. "In response, I pulled my hair into a pony tail and walked out of his office with my nose in the air."

The dependencies of childhood—for nurture, instruction, and approval from adults—were often especially hard for these women to outgrow, though virtually all of them appear to have succeeded. The transition was not always a happy one. "As a child I was very

much treated like a cosseted princess: dressed in beautiful clothes and sheltered from the outside world," wrote thirty-two-year-old Karyna Laroche, whose muscular dystrophy requires her to rely on caregivers for virtually all her needs. An outstanding student, she attended a special school for disabled students until, at thirteen, she transferred to a regular high school, where "I finally realized just how different I was from other kids, how being disabled was only considered cute and socially acceptable when one is young, otherwise it is a social embarrassment." The shock was so great that, despite outward success, "inwardly I only wanted to die. My first suicide attempt occurred at the age of 16 and suicide plans and attempts continued until I turned 30." Only then did she discover "just how lucky I was to be living on my own (which I love), to have great friends, and to have the chance to build a life based on my needs rather than on others' expectations of me."

More often, simply entering adulthood brought a new rush of self-confidence. When Michele Anne Hope Micheline, a student at Emory University whose spina bifida, though relatively mild, has necessitated a number of operations on her left foot, developed a severe ulcer on her normal right foot during her freshman year, the doctors wanted to amputate the infected bone. "I realized," she reported, "almost like a slap on my face, that I was old enough to tell them that [surgery] was NOT how I wanted it. I had a right to say no, to get a second opinion. To grasp my life." Finding a doctor in whom she had complete confidence, who was able to save all but half of her big toe, and having her left foot

reconstructed, she assumed responsibility for her own well-being. She has come to terms with the fact that she will always have to deal with a disability and that doctors, though useful, "can't give you a perfect foot. They can't give you what God didn't. You have to find a substitute within yourself for what you are lacking."

Some respondents had already reached adulthood when, like me, they developed a disabling disease or else were injured in skiing, motorcycle, automobile, or on-the-job accidents—even, in one case, a tornado. After I learned that I had multiple sclerosis, the transitions I had to make, involving the development of a new sense of who I was and what I was good for, required mourning the loss of the "old me" as I confronted a new one who seemed like a stranger. The active young wife and mother faded: no longer could I run after my young children or dance with their father. When my waist-length hair grew too heavy for my weakening hands to wash and brush, I had to cut it off, and suddenly I felt no longer carefree and sexy but practical and matronly. With degenerative conditions like mine, self-definition may have to be revised in this way again and again as new limitations develop.

For those struck by sudden catastrophe, the need to adjust may have come instantly, but the process itself took time. Muffy Davis was fifteen, training to be an Olympic ski racer, when an accident on the slopes left her paralyzed from mid-chest down. "It always amazed me when people would say, 'I don't know how you do it. I could never do it!' You don't have a choice, you just do it! What most people don't realize is that they would do

this also. They see a disabled person and immediately put themselves in that person's shoes. What they don't realize is that disabled person didn't just get to wherever she was right away. It took time and grieving, but slowly day by day she got better, and eventually she was right back to attacking life, like she had been before her disability." After graduating from Stanford and before beginning medical school, Muffy plans to "give myself a shot at ski racing again, this time as a disabled athlete. I don't want to have any regrets when I get older." Thanks to adaptive sports equipment, such a goal is within her reach.

Whether gradually or suddenly, disabilities that occur in adulthood require revisions of identity that can yield fresh insight, as Madeline Cohen, who has a degenerative retinal disease in addition to her 85 to 90 percent hearing loss, discovered during a three-week *Outward Bound* experience after college graduation. "Had I stumbled over your disability survey announcement a few years ago, I might have continued flipping through the magazine with little more than a passing glance," she wrote, because she did not grow up defining herself as disabled. On *Outward Bound*, she encountered "a virtual assault of obstacles. Not the least of these was learning to recognize my limitations, voice them to my group members, and accept assistance from those around me. The latter was (and remains) the most difficult." As the days went by, she came to perceive that "everyone in my group carried special needs [one, for instance, was terrified of heights, and Madeline was able to talk him through a scary climb] and that by accepting

assistance, I was acknowledging my participation in the cooperative human endeavor. Since that time, I have been learning to define myself as a 'person with a disability.'"

Regardless of when their disabled lives began or what pattern they have followed, all the respondents confronted the same issues in the "cooperative human endeavor" known as life as did their nondisabled peers. "People seem surprised and often patronizing when they find out I have a job and a social life," wrote Peggy Merriman, who works for a nonprofit agency assisting released prisoners, as though disability drained away all the interest taken by normal young women (and some of us who are not so young!) in finding meaningful work and developing personal relationships. On the contrary! Despite the enormous variety of their experiences, virtually all the respondents devoted much of their energy to the issues surrounding career and love.

A number were still undergraduate or graduate students, majoring in a variety of fields from art history to animal physiology. Those who had finished school worked in similarly diverse areas, among them education, management, law, health care, and fashion design. Disability often required them to be both flexible and resourceful. "At first I wanted to become a vet," wrote Naomi Passman, "but saw how much lifting was involved and decided against it." Determined to work with animals, she applied to become an apprentice trainer of assistance dogs, but the director of the school turned her down. "I couldn't believe that a person who

provided a service for the disabled would not hire me because I *was* disabled!" Undaunted, she found another program. "I am an Apprentice Assistance Dog Trainer and an Independent Living Specialist. I LOVE my work," she reported.

Even though the Americans with Disabilities Act is supposed to prevent the kind of rejection Naomi experienced, a few of the respondents had encountered outright bias, including retaliation by employers if they applied for workers' compensation after being injured on the job. Felicia Wells Williams, with a bachelor's degree in social work, started her career as an entry-level receptionist. "Once after observing blatant discrimination, I filed an equal employment opportunity suit with the Defense Contract Administration/Department of Defense," she recounted. "With the help of some knowledgeable friends, I not only won my case, but I was given the higher grade plus back pay." Defending one's rights can be tricky, however, since the nondisabled tend to expect people with disabilities to be unfailingly cheerful and passive, as Felicia has learned: "Some people say I am arrogant but I believe if I were of normal height/not disabled, I would be called 'confident' rather than 'bossy' or 'pushy.'"

More subtle forms of intolerance can make the workplace a chilly one for disabled women. "Because my symptoms tend to be invisible, I haven't experienced any real bias or discrimination" as a policy advisor to an elected official, reported Cece Hughley Noel, who has had multiple sclerosis since 1987. "However, on the days that I need a cane it is very difficult for me emo-

tionally. People who I work with every day fail to recognize me on the street. They tend to avert their eyes from 'cripples' and don't meet my eyes or hear my 'hello.' It can be devastating to win their praise for taking charge of a meeting one day, only to be ignored as a 'gimp' on the street, the next." Dealing with pain and fatigue every day, Cece has found herself being resented as well as ignored: "My co-workers get 'snitty' sometimes when I take a break and lie down in my office or leave early."

In addition, Cece wrote, "I've used up all my vacation and sick leave this year and feel as though my back is up against the wall." Some of the respondents, finding themselves in similar situations, have had to give up their jobs, and their comments revealed that in our work-driven society, where what you "do" determines who you "are," lack of employment can erode one's sense of self-worth (not to mention one's bank account). As Stephanie McCarty, who managed a bookstore for ten years until her MS symptoms forced her to go on Social Security Disability, put it, "I often feel flustered when I am asked what I 'do' for a living (they wouldn't believe what I do just to live) and don't quite know what to say. I take classes in pottery, spend a great deal of time in the library (and doctor's office), keep myself busy on my home computer, and concentrate on staying healthy. But these things all seem pretty benign when I am talking to someone with a 'career.'"

Whether they held paid jobs or not, these women craved social contact, even at the risk of awkward encounters.

Many recognized that what seems to be rudeness on the part of nondisabled people often arises from ignorance and fear, which can be more crippling in their own way than a physical disability, and that the best way to relieve these is through education. Their advice was pragmatic: Treat a disabled person as an intelligent and responsible adult. (If she's not, that's her problem, not yours.) Remember that not all disabilities are apparent before you accuse her of malingering or shout at her for taking a handicapped parking space. NEVER take one of these yourself, even if you'll "only be a minute." If she does have an obvious disability, before rushing to her aid, ask "How may I help?" and then follow her instructions carefully, or you may both wind up in a heap on the floor. If she's in a wheelchair, sit down whenever possible so that you can converse eye-to-eye, not eye-to-navel. Don't ask her any questions more personal than you'd feel comfortable answering yourself. ("What's wrong with you?" is probably not one of them.) Above all, don't offer her pity. She probably doesn't need it. (And when she does, she can take care of the job herself.)

Many spoke warmly of friends who offer, as one anonymous respondent who was left partially paralyzed by a brain tumor put it, "kindness without condescension." Most of these friends were not disabled, although some of the women still in college reported involvement in disabled students' groups, and most accommodated a disability without much fuss. With both her hearing and her vision impaired, Madeline Cohen has found

that "the people who know me best are great about things like repeating themselves, steering me through dark bars and parking lots, and understanding when I miss the thread of a large, noisy conversation and say something ridiculously unconnected. My friends are used to seeing me bump into any object lower than hip level, collide with small children, and look around blankly for someone standing directly in front of me; they do as much as possible to help me avoid such mishaps without making me feel inadequate or foolish."

Sometimes thoughtless friends cause pain without meaning to. Maree Larson, an assistant producer for a video production company who has spina bifida, recalled attending a political rally with some friends, all but one of whom "walked up the steps and took their seats in the third row," while her wheelchair required her to stay in the first. "Soon, my friend was persuaded to join the others ('but only for a minute,' she said), and I was left by myself for the remaining 20 minutes before the rally began." Even friends who are sympathetic in one area can be insensitive in another, as Konie Gardner discovered when it came to dating: "I can't begin to count the number of times that well-meaning friends would say to me, 'I'll set you up with. . . .'" and every time, and I do mean every time, they never once did. I don't think people realize how much a person like me clings to every promise, suggestion, or hint that is made in this regard."

In general, these women found romantic and sexual relationships much more difficult to establish and sus-

tain than simple friendships. A number were troubled by the prevailing social perception of disabled women as incapable of and uninterested in sex: "In this culture people with disabilities are expected to be perpetual children which means that sexual expression would not be appropriate and may be considered perverted," observed Pat Danielson, whose juvenile rheumatoid arthritis was diagnosed when she was four; and twenty-three-year-old Kimberly Mangiafico, who has spinal muscular atrophy, protested that her wheelchair gives most men "the impression that I cannot have sex, which is totally not true. I have a great sexual self-image and I am really comfortable in my own skin." Others recognized internal barriers, like Naomi Passman, who reflected, "I have had boyfriends and even a first love. That part has never been a problem for me; however, when it comes to being sexually involved that's when walls go up. Quite honestly, for me it has not been other people's perceptions that have affected the relationships, it has been my own."

Knowing that they, like nondisabled women, will be judged initially on their appearance, many reported taking great care with their clothes, makeup, and hair. Some were aware of the obvious ironies of this emphasis, like Peggy Merriman, who asked a male friend, "in my most unconcerned and disinterested voice, if he thought any guy would *ever* want to meet or go out with me or even be seen with me, if I was using a wheelchair" and was told, "I don't think it really matters that you're in a wheelchair, because you're so pretty." "Here I was," she went on, "ashamed and embarrassed, because of my

physical body. Here he was, praising me and telling me I had nothing to worry about, because of my physical body. He didn't say, 'It doesn't matter, because you are so interesting and intelligent,' or even, 'It doesn't matter, because you have such a cute dog, and anyone who wants to play with him knows you and he are a package deal, unfortunately.' *That is me; that's who I am.*"

No matter how pretty or smart a woman may be, or how cute her dog is, "dating and initiating a relationship is difficult though because all of the typical rules never seem to apply when you are in a wheelchair," noted Muffy Davis. "Guys feel that they can really flirt with a girl in a chair but they don't see it as anything serious," since she presumably doesn't expect to be asked out. "Also girls with disabilities can put all the moves on guys and yet the guys will never interpret things the right way." Although she has found that she often has to take the lead, "I really like it when, every once in a while, a guy makes the first move."

Too often, however, he doesn't make any move at all. "I am 27 years old and still a virgin, not that that is bad, but only that it is really not by my choice," wrote Kim Silvey. "I had a date to my prom when I was a junior in high school and went out on a couple of 'just friends' dates in college, but that is it." But disability didn't take away her dreams: "I want nothing more in life than to get married and have a soul-mate, best friend, and lover for life. As each birthday comes and goes, I feel the reality of such happening getting smaller and smaller, and I feel cheated and angry."

Those who had succeeded in establishing relation-

ships often found them complicated, physically and emotionally, by disability. "I worry about what weird noises my body is making that he can hear and I don't," Juli Delzer confided. And a woman who asked to remain anonymous wrote, "Unfortunately, spina bifida did affect my sexual functioning, and I'm not able to achieve orgasm. While we've been able to have a reasonably satisfying sex life without intercourse, I know it bothers my partner that I'm non-orgasmic. I think he sometimes sees it as his failure. I'm very responsive to foreplay with my breasts and around my neck, but am truthfully disappointed myself not to be able to climax." "Due to numbness, weakness, fatigue, and bladder problems we sometimes have to be creative with our lovemaking," noted Stephanie McCarty. A sense of humor also helps: "Often, in the heat of passion, one of my hearing aids will be pressed against a chest, an arm, or a pillow," creating an electronic squeal, wrote Madeline Cohen. "My line, dating back to junior high school: 'Whoops! That's my parents checking up on me.'"

Sometimes the urgency to find a partner contributed to an unwise choice, leading to grief. At twenty-nine, Frances Wallen was paralyzed from the waist down when an 18-wheeler ran a stop sign and struck her red Mazda RX-7. "Before the accident I'd been dating someone fairly seriously," she recalled. "He was wild and unreliable, but I was crazy about him and our affair was very hot. After the accident he was there for me every day and we talked about marriage. I wanted as much of my life back as possible, and figured that this was my

last shot at love with someone who could see me without pity. My new husband didn't pity me—he resented me, and took great pleasure in draining me dry financially. I figured he would settle down eventually, but he didn't. We divorced after a year and a half, and I added a broken heart to my list of all my other broken body parts."

But there were happy stories as well. One respondent's husband had abandoned her and their three small children when she was still only mildly disabled by a childhood bout with polio; later, post-polio syndrome caused increasing pain and fatigue, a limp, and breathing problems. At this point, she became friends with a man at the agency where she worked. "He talked to me and we found common ground in our children and love of music," she recollected. "While out in the field I came back to agency headquarters occasionally, and he'd be there, interested in my latest news. When I was moved back on my medical transfer, last year, our friendship grew. I told him, up front, about the polio and the part it played in my life. We married in April 1994. He is there for me, supportive and encouraging and loving. In his eyes I am beautiful, the fact that I have polio doesn't interfere. Through him, I am learning to do my best without exhausting all my energy to 'measure up.' Through him, I've found self-acceptance, self-pride, and love. I look in the mirror and see *normal*."

Fortunately, this experience was far from unique. As Muffy Davis pointed out, "The phone does ring less often, but the guys who do call and are interested are of

a higher quality." She's been with one of them for two and a half years now, and many other respondents reported similar good fortune, finding partners who were perceptive, patient, affectionate, and above all reassuring. One respondent, whose brain tumor left her with partial paralysis, as well as hair loss and weight gain, wrote, "Naturally, I don't feel very sexy any more. Yet my husband has continued to treat me with kindness and tenderness. Because of his accepting attitude, my self-esteem has not plummeted entirely." Barbara Maguire, married with two small sons, reflected on her fear that her cerebral palsy might be a burden to her family: "Perhaps my biggest fear is for my husband to someday find out that I am not worth the struggles we've had. He assures me that he is the lucky one and that I am the one 'putting up' with him." "I presently have someone in my life and he is a sweetheart," wrote twenty-five-year-old Stacey Fujii, whose lupus was diagnosed on her twenty-third birthday. "Although he is a surfer, he will do things with me that do not involve the sun, like going out to dinner, to a movie or for a walk on the beach at night. It was very hard for me at first because I felt as if I were holding him back. I was also very insecure about the person I am now, but he always tells me I am beautiful and incredible for what I had to go through. He takes the best care of me and never says I am different, just special."

Not perfect, perhaps, but both normal and special: just the way every woman needs to feel. And aided by parents, teachers, friends, lovers, and/or sheer self-

determination, the majority of the women who responded had achieved some sense of their own ordinary yet unique qualities. Like Madeline Cohen, they had gained an insight into the human condition which enabled them to see their disabilities as "simply a part of who I am, just as other people have lost parents, gone through divorces, overcome learning disabilities or major illnesses, pulled themselves out of socioeconomic deprivation, or emigrated from war zones." Surely not all would go as far as Kimberly Mangiafico when she wrote that "if I was suddenly given the chance to be able to walk, I would not take it. My being in a wheelchair is part of who I am." But most would understand the self-acceptance her statement implies.

Over all, the women who chose to reveal themselves to *Glamour* were bright, tough, competent, sometimes angry, often funny, and very self-assured—hardly a whiner in the bunch! Theirs were not, as cancer survivor Pat Wallace put it, "triumph-over-tragedy stories" (though there were plenty of tragedies and some triumphs, too) but adventure stories. Stephanie McCarty echoed the sense I often have of exploring uncharted territory: "I feel I have been sent on a journey. I wasn't given a guidebook, so I'll have to draw my own map." In undertaking to live as full human beings in a world intent on reducing them to a set of dysfunctional limbs and organs, they had grown much more vigorous than their sometimes fragile bodies would suggest. As I read and digested their words, I felt honored to count myself among their number.