

Shadow Boxing No More: Dispatches from the MS Wars

Excerpts from the 2004 notebook of a Carmel clinical psychologist who was also President of a local non-profit service group. The group is dedicated to helping bring patient-empowering services to the Central Coast population of self-styled medical orphans” suffering from Multiple Sclerosis, an incurable debilitating disease of the central nervous system—one of the still-unsolved puzzles of modern Medicine. *The persons cited below are composites of real patients to protect confidentiality.*

Hurrah: Good news! Today, August 1, 2004, our non-profit group, the Multiple Sclerosis Quality of Life Project (MSQLP) received a \$25,000 grant from the Local Opportunities Fund of the California Endowment! This sum, combined with a previous \$6,000 grant from our Local Community Foundation for Monterey County, as well as other grants from the EOS Foundation in Texas, Teva Neuroscience, Yellow Brick Road Thrift Shop, Monterey Peninsula Volunteer Association and other individual donations, will enable us to immediately hire a qualified Medical Social Worker/Case Manager on a half time basis to work with various MS patients in their own homes during the course of a year. The social worker will help them cope with the day-to-day energy-draining health and housekeeping problems that pop up; will mediate the accumulated estrangement what builds between chronically ill patients (with their repeatedly frustrated expectations of improvement or even cure) and their often beleaguered, harried medical providers (who self-protectively retreat, at times, from too-intimate a contact with patients to whom they know they can offer, at best, only palliative relief).

Now we can go ahead, too, with our plan of running regularly scheduled MS support groups at the Oldemeyer Center in Seaside, getting our newly designed MS web site up and running as an information and referral source for the whole tri-country area (Monterey, Santa Cruz, San Benito) and devising new ways to educate the public in general, not only about the social, economic and psychological ramifications of an illness like MS, but also of other similar chronic diseases whose victims, in our present “recidivist” era of increasing medical cutbacks, amidst continuing paeans to the glories of “privatization”(translation: good riddance to government “handouts”), wholesale clinic

and hospital closings, declining numbers of adequately insured citizens, brutally mushrooming medical costs. Chronically ill persons have come to depend more and more on modest efforts such as ours. These efforts, I have come to believe, seem to be taking on an increasingly urgent sort of “emergency room” survivalist role with each passing day.

It is hard to convey how many “average” daily functional constraints the 300 to 600 MS patients in our central coast area have to contend with day after day. When we polled a representative sample of this community, comprising 80 MS patients and 25 fulltime caregivers 2 yrs ago, we seem to have tapped into a despairing level of resignation. Nine out of ten persons questioned put the amount of derangement the illness was causing in their everyday lives at 90 percent—nine out of ten on a scale of ten! And the replies were dishearteningly similar, too, when it came to the ratio between the duration of the disease and the number of medications taken. No matter when MS had been identified—whether 6 months or 10 yrs ago—those with, say, only 2 or 3 symptoms reported themselves as having to take up to 4 to 6 medications a day, the same number as those with twice as many symptoms! And the radical uncertainties this illness poses—its unpredictable twists and turns, its sudden disappearances and infuriating arbitrary relapses, the way it seems to play possum and then, all of a sudden, heartbreakingly ambushes you from out of nowhere—appears to leave a residue in many respondents of anticipatory flinching, a sort of ongoing “background” anxiety that this or that greatly looked-forward to event, trip, appointment may have to be abruptly avoided or postponed because of a sudden MS flare-up. It represents the fear, for instance, that a crucial Doctor’s appointment planned weeks in advance may have to be cancelled at the last minute since the day that it is scheduled to happen—because of the notorious “up” and “down” Russian roulette contingencies of MS itself—may turn out to be a “bad” day, a day when the patient may simply not be “up” enough to give a adequate or accurate account of what he/she may be going through.

Telling people that MS is a disease which attacks the myelin sheath—the “insulation” protecting the neuronal circuitry in the body and thus can affect all the “endpoints” this circuitry is attached to—vision, motor function, cognition, digestion, elimination, etc.—is apt to get you puzzled stares. So I’ve learned to use the metaphor of

a house with innumerable rooms. One day, the insulation in the invisible wiring behind the walls of this house mysteriously begins to peel off here and there, we don't know why, causing sudden short circuits or breakdowns in the heating system, the kitchen appliances, the utility room, etc. depriving some—or all—of these areas of essential power. The shut-off may last for days, weeks, months, even years. Then—just as suddenly and inexplicably—the power may come back on. For some MS patients, the fear is not only not knowing *when* the power shortage may strike—it's also not knowing *where*. Thus everything that goes into the normal cycle of daily functioning we take for granted—walking, seeing, standing, hearing, eating, thinking, going to the bathroom—with MS becomes potentially at risk. In today's age of medical compartmentalization, those certified as experts in such various body systems—neurologists, urologists, gastroenterologists, orthopedists, internist, psychiatrists—frequently find themselves talking past one another. As a psychologist, I've learned myself firsthand that psychiatry in particular sometimes has an uneasy time, for instance, connecting with both psychology and neurology. Thus, MS sufferers are often forced to field questions thrown at them from bewilderingly divergent medical viewpoints. They may end up trying to cobble together impromptu home-grown coping mechanisms based on brief unevenly spaced treatment sessions conducted by their constantly revolving corps of specialists. To be compelled to be on the receiving end of this sort of medical yo-yo act over a decades-long course of an illness like MS—say over 15 to 35 and more years—is enough to make any patient eventually lose hope of control over the evolution of his or her own illness, yielding up in the process not only any sense of personal autonomy, but harboring as well a bitter bottom-line conviction that *nobody* in fact—through the whole long obstacle course gauntlet that MS frequently amounts to—has been willing to step up and take overall responsibility for the direction and control of this notoriously hit-and-run terrorist-like malady that is punctuating—and overlaying—their lives. Moral: There *is* no “typical” MS patient! MS, a condition that can hit at so many areas of daily living, is truly a moving target; its only consistency is inconsistency itself.

I should acknowledge at this point, I think, that—though I'm about to discuss some local body-and-spirit depleting instances of what we've come to call MS “orphans”—those whose condition has left them house-bound, socially isolated,

exhausted, and often struggling at the outer limits of their waning resources, emotional, financial, familial, and physiological—there are others suffering from the same disease, who, paradoxically, are still able (with the help of a few intermittently effective symptomatic remedies) to follow their daily routines, with—*up to now*—tolerable levels of interference with their “normal” lives. Notice, I’ve put the words *up to now* in cautionary italics because where MS is concerned, *everything* has to be considered provisional; there is *always* a kind of figurative booby trap lurking in the background, threatening problematic future contingencies which any MS patient may have to confront at one time or another. The statistics, again, are instructive. They tell us that those after diagnosis who’ll be able to go through life only marginally affected—10 to 15%—are about the same in number as those who, from the outset—5 to 10%—will rapidly decline in a downward plunge toward general invalidism and the critical impairment of major bodily systems. The remaining 75 to 80% after diagnosis will suffer in greater or lesser degree from the more characteristic relapsing-remitting form of MS: about *half of these* will continue to exhibit the characteristic “toggle switch” on-again off-again pattern of the illness, some suffering more severe outbreaks than others. In the other half, that periodic liberation from symptoms will eventually vanish entirely; from then on, their progression will be steadily downward, though at differing rates of speed. And about a third of the entire group, whether relapsing-remitting cases or slower or faster progressive ones (“primary” or “secondary” progressive labels) are destined to end up the latter part of their lives in wheel chairs. Confronted with such numerically daunting perspectives, some medical providers may tend, understandably, to flinch. Others, on the other hand, seem to dig in their heels, as it were, finding admirable ways to battle MS on its own terms, in the nitty-gritty trenches of the daily grind.

One such practitioner who has been an inspiration to us in the past is Dr Michael Berlly, of San Jose, a physician specializing in rehabilitative medicine. Years ago at a medical conference, Dr Berlly traced the many “little” ways by which—if one was tenacious, patient, inventive, and meticulous in taking an airplane view of the whole spectrum of a patient’s needs, one could end up truly making a difference. At that time he evoked an MS patient named “Kathy” who was overwhelmed by the *tsunami* of her practical problems. MS was preventing her, according to Dr Berlly, from “*taking care of*

her own children, being a homemaker or even an adequate wife (with the attendant guilt this caused)”. “Kathy” also confessed how embarrassing it could be not to be able to clean yourself sufficiently...and her work was becoming more and more difficult since she had to operate a microscope with poor hand dexterity and run a lab when she was too fatigued to take proper care of herself and her family....And other fears—the fear of incontinence, of the collapse of her own handwriting, of her inability to get any exercise—were beginning to dominate her thoughts....” Since he was working out of a teaching medical center, Dr Berlly was able to draw upon a cadre of specialists. Thus “Kathy” was sent off for a multiplicity of tests and assessments by neurologists, occupational and physical therapists, speech pathologists, MFCC counselors, and so on. The result was an intricately orchestrated rehabilitative scenario centered in four areas: 1) Restructuring family tasks, discarding the ones she could no longer accomplish; 2) Learning how to say “No” during speech pathology, without guilt; 3) Redesigning her kitchen and her life with MS-friendly tools, enabling her to do simple but essential things, like turning off faucets, unlocking her car; 4) Becoming gradually able—through counseling sessions—to convey her daily needs to her family so that they’d become less dependent on her, more supportive of her actual situation. What Dr Berlly intended to illustrate, of course, was the functional value of rehabilitative medicine. But what he was really demonstrating, so far as I’m concerned, was the restorative power of a transformed mind-set. By treating “Kathy” as a whole person, by awarding her the largesse of time and respect her illness deserved, and by infusing her with some of his own confidence and hope, he was able to help her integrate her many problems within a picture of an ascending—but realizable—ladder of possibilities. He gave her a vision, in other words, of how to cope. And by coping, “Kathy” was able to avoid the luckless role of chronic (or even, at times, tyrannical) invalid living with “*learned helplessness*”, as one doctor described it, which MS, like other chronic diseases, is constantly ready to tempt you into embracing, and which our own local efforts at MSQLP is similarly dedicated to nullifying whenever possible, through whatever means—psychological, clinical, institutional—we’re able to muster.

“Susie”, who’s had MS for 15 yrs, first noticed her “weak, left leg” was going flabby on her—at odd times and places, out shopping, say, or crossing the road—nearly a

year ago. But at first she simply tried to “ignore” it. Someone at her support group, though, saw what was going on. “Better start thinking about a wheelchair”, he suggested. Susie couldn’t hear it, didn’t want to admit that things had “gotten this bad” (she had always looked at her wheelchair-bound comrades with a certain commiserating pity). Another reason: she plain couldn’t afford it! Some years ago, when she still could work, she’d made a substantial sum in Real Estate. But by her 15th year with MS, this money had shrunk away. And her husband kept refusing to discuss the subject of money, kept hinting that it might be time for her to look for a caretaking facility. “Hey, tryin’ to get rid of me?” Susie teased him, only half in jest. Getting a wheelchair suddenly seemed threatening not only to her bank account, but to a change in her husband’s attitude, the very stability of her marriage itself. And the cost—\$1,200 for a wheelchair? Out of her league!

Thus, for the first time, she found herself applying for “charity”, something she swore she’d never do. She appealed to two local long-time MS charities, one in San Jose, one in Salinas, trying to follow their protocols as best she could. “Never in my whole life”, she declared plaintively to her support group, “did I expect to have to be begging for *charity*.” “Look, honey,” advised another Support Group member (who’d already been through the humiliation of the charity-mongering mill and had lived to tell the tale). “Do whatever you have to do—and then just keep right on doing it.” It took six weeks for Susie to get a reply which was, according her, “*like waiting for the lottery*.” Then, two days in succession, \$200 appeared in her mailbox from both local organizations. One told her they’d nearly exhausted their annual budget for “equipment assistance”; another declared they were “*not allowed to give more than \$200 in aid for any one request*.” So eventually Susie found herself doing what so many others do nowadays when hard up for cash—she put \$700 on her credit card, praying that her husband’s earnings as a free-lance cabinet-maker would eventually help her to pay off the balance—at 17.5% interest! Nevertheless, there was a short moment of triumph when she was able to ride in on her new chair one Saturday morning to her support group meeting, mischievously parodying a collision-bound amusement park rider, but just managing somehow to manipulate her machine safely round corridors so as to be able to avoid bumping into walls, chairs, lamps, tables, and everything else in sight. .A wide-eyed member asked her: “Hey, your

leg's gonna stop twitching now, right? Susie made an ironic negative grimace. Then she demonstrated her homegrown method of taming her out-of-control limb. "*Voila!*" she said. She pulled out a rubber strap—a suitcase strap—that had been hanging over the steering wheel. Holding it in her mouth, she wrapped it round the sides of the wheelchair and under her leg, then snapped the two ends together, pulling the strap tight until the rebellious twitching stopped. "*Ta-Dah!*" Susie cried, triumphant. From the Support Group, came spontaneous applause.

A support group, of course, is a place where folks can relax and let go. As many of my clients have testified though, to the uninitiated on the "outside" MS is a kind of deceptively hidden condition that does not always "show" its stigmata (like, say, a broken arm.) "*Hey, you're looking great today,*" well-meaning friends used to say to Paul, another of my MS clients, a greeting he used to cheerfully acknowledge, congratulating himself on the "front" he was able to stand erect while at the same time raging inside at the split that actually existed between the way he *looked*, and the (miserable) way he *felt* ! When his left leg began to act truant recently, however, dragging behind him so he could no longer stand upright or get up from a chair unassisted, he knew the game was up: the masquerade was over, he'd no longer be able to pretend that everything was okay. And then he began wondering about all the consequences that might follow. Now that he was "outed", how long would they let him continue to work? How would he be able to make the payments on his house? And where would he get the money to support his daughter through college? Plainly, what Paul really needed right then was not the services of a medical specialist—a neurologist or an internist; what he needed was someone to talk him through the latest of an endlessly recurring series of MS-connected crises. As he'd learned over the years, however, Paul began automatically parrying his concerns with a joke. "Hey, guess what?" he told me. "Now I'm going to have to give up my crown as neighborhood Polka King for sure." Then he laughed, putting on his MS public face, that protective mask I've seen many times as MS victims indulge in what the Germans like to call "*galgen Humor*" or gallows humor, making the best of a bad turn of events with a quip aimed directly at themselves and their (enigmatic) infirmity.

In the case of Doris, though, an ex librarian now retired, *her* right leg is no longer merely fitfully non-cooperative; it has become, in fact, permanently Absent Without

Leave! Very slowly, over 10 years time, it has gone from “numb to useless.” Not that its absence bothers her so much any more. Her real problem, she confesses, is that her four-poster bed that she once gloried in now seems suddenly nearly out of reach! Come bedtime, she worries whether her lagging leg will be able, in fact, to make it up under the covers. She’s tried using various pieces of furniture as assists—bar stool, chair, hamper—but her perversely disobedient limb, heavy as a stone, simply refuses to go where she wants it to go. “Hey, get a dog leash, why don’t you?” Susie suggests, from the sanctuary of her leg-wrapped wheel chair. “First tie the damn thing to the headboard. And then, when you’re propped up on your good leg, just reel it in like a fish!”

Improvisation, of course, is one of the strategies persons with MS have to learn to depend upon all the time: those who push themselves to try to figure out ways to outwit—or sneak around—continually changing household or workplace roadblocks, those who somehow develop more patience to deal with the “defiance” or intractability of mere inanimate objects, such as beds that “resist” being climbed into, or an extensor knife whose blade perversely “refuses” to retract, or a heat vest that seems to “prevent” its use by mischievously knotting its tethers—will not get as downcast or despairing, I’ve found, as those who automatically flinch from the pitfalls, dangers, and booby traps they can’t help seeing everywhere. So many MS patients, in my experience, have learned to improvise their way through a gauntlet of nitty-gritty details, copying remedies from one another, braced against the possibility of one pratfall after another. But struggling in this way—and even managing a rueful quip or two at the sometimes patent “absurdity” of their Laurel and Hardy household routines—helps them not only retain their self-respect; it gives them a certain detachment and even a defense against that lurking seed of self-pity that all chronic illness sufferers sometimes are prone to. So long as they can eventually laugh—even though it hurts—chances are good they’ll be able to get up and fight another day.

Two weeks ago, I was called to assess the splendors of a brand new customized MS-ready van, that Phyllis, a MS patient in her fifties, had just been able to purchase through the generosity of a local philanthropist. When I arrived, Phyllis was seated on the floor in a room that has been adapted to her multiple needs. Everywhere there were still evidences of her pre-MS former life: photos of Phyllis with horses she *used* to ride; dogs

she *used* to train, instruments she *used* to play. There was also a collection of wooden pigs, which, she told me, are the cleverest animal of them all. They're the only ones, she suggested, that satisfy their sensuality by rolling around in the mud. She laughed when she told me this. "We MS folks, you know, we're all touch-deprived!" she said. Phyllis has had MS for over 30 years. She's a pro, a veteran. The remote channel switcher to the TV that was temporarily silent, held by a ribbon hanging next to an old well-worn wheelchair; the corgi dog at her feet—her important contact with the world—can be coaxed to fetch the newspaper, to bring her the coke bottle that her weakened arm sometimes can, and sometimes can't, hold; to lift up her cane, one of her no longer entirely useful tools because its owner can no longer dependably stand alone unaided. The bed to which she has to be transferred with the help of an aide had papers spread out on it, "*but for the life of me I can't remember why I put them there,*" she laughed.

That day, as I watched, Phyllis was using her teeth and her tongue to open the top of a water bottle while her useless right arm was resting under it. At the same time, her left shoulder was trying to maneuver her left arm into the hole of a T-shirt which, in an impish mood, was "refusing" to allow itself to be opened up wide enough for her arm to get through! "I know I'm probably going to cry soon," Phyllis says. "But I still intend to drive my new van out to the Monterey Sports Center today just to get out of here. Getting out anywhere, even for a little while, helps me escape that sort of cat-in-a-cage feeling that comes over you when you have to go up and down or back and forth or around and around and around the same identical rooms day after day after day for the zillionth time." When she'd finally gotten herself settled into the driver's seat of the new van, she gingerly began inching her butt over to the brand new wheelchair on her right, while both legs were left momentarily behind "*sort of like dead meat.*" Then, using her hands, she managed to wiggle one leg at a time into the chair. Next, she slowly, in fits and starts, backed the wheelchair to the center of the van, positioned herself on it, and—with an electronic wand—opened and closed the sliding side fiberglass doors several times. Then she grinned at me at last, ready for applause, which I, of course, her audience of one, gratefully gave her.

Today, though, when I visit her again, the scene has altogether changed: her afternoons have suddenly become harrowing for Phyllis, because, when she goes to her

room after lunch, she suddenly finds herself drained of energy. She tries to speculate on what the reasons might be. Perhaps she's mourning her mother who died recently? Perhaps it's because she's recognizing that her MS is getting worse? Perhaps she's worried about the health of her 80-year old father who has to take care of her in her fifties, a role reversal she really hates?

Last week, though, Phyllis suffered the worst blow of all: she had to be rushed to the emergency room because she had a fever spike, which, it turned out, was the result of a urinary infection. When she came home, she was confused and disoriented. She discovered that she had forgotten to take her hormone pills which—supposedly—help her mood swings. “*But who knows?*” she declared. “*Maybe they do and maybe they don't.*” The upheaval was so exhausting to both patient and caregiver that they called her private physician, who in turn called on the local hospital's Home Health Services to check her out. The person who happened to respond, though, turned out to be the hospital's “official” hospice representative. “Could Phyllis go there for a few days for a little recuperative R and R?” he was asked. “Sorry,” the answer came. Obviously, Phyllis was not anyway near the end-stage of MS and so therefore the hospice, unfortunately, had to be ruled out. The next day, we at MSQLP called the Home Health Agency (now run by the Community Hospital of the Monterey Peninsula, CHOMP) and the home health aide said, “I'm afraid we can't give the patient home care service because apparently she still goes and works out from time to time at adaptive Physical Ed. at Monterey Peninsula College. Our services are supposed to be reserved *only* for the *totally* house bound, you know.” Phyllis is crying freely now as she hears my end of the conversation and guesses the rest. “So the bottom line seems to be,” she says, “I have to be nearly dead for one agency to help me, right? Or twice as sick as I actually am, to get any help from the other.”

Wait, it only gets worse! Later on, acting as impromptu social worker, I tried remanding her for a few days to a private nursing home, allegedly catering to convalescents. But they decided they couldn't take her either. Why? Because, apparently, she needs to be strapped at certain times into her wheelchair. What if the catch should slip? What if she happened to *fall*? She might cause them to lose their license! Or, even worse, sue them and put them out of business altogether! So Phyllis, in her present

condition, seems to be a big “no-no”, a sort of medical “untouchable,” definitely off-limits to existing service agencies and, apparently, ineligible for all the would-be supplementary help so cheerfully—and regularly— advertised as “officially” available for all persons “truly” in need.

Obviously, I have to resist going around like Chicken Little crying “the sky is falling, the sky is falling,” all the time. But each day I can’t help being reminded in so many ways how much the health care system is failing us. The safety net is not only ripped—it’s shredded in a thousand places! We’ve lost the public bond vote for preserving free services for our local county hospital. Now a nearby combination senior residence and facility for handicapped folks seems to be in very delicate financial shape; it may or may not be saved; Medicare is lowering its fees to doctors, even while health care costs keep rising exponentially. And the health star in our local health firmament, CHOMP has just closed its home health services because, (they say) it’s losing them \$2,000,000 a year (even though they’ve just finished building a giant new state-of-the-art parking garage whose total cost is reputed to come to at least that amount.)

Furthermore, because our terminator-governor thinks we are incorrigibly addicted spenders, the Olmstead Decision, which in theory gives handicapped folks the right to demand they be cared for in their own homes, has yet to be implemented. In an age of contagious medical specialization and the increasing loss of the old-fashioned family doctor we simply do not have, in our semi-rural area, the numbers of patients that warrant centralized services—medical, rehabilitative or psychosocial—the kind Los Angeles, say, or New York can afford to provide. But our MS clients need somebody who’s truly prepared to tune in to them, not just as persons with MS but as beings with a life *outside* of MS; not just as “handicapped victims” but as living sentient human creatures, each one inimitable, some of whom have this or that disability to contend with. “*Independent living*”, we think, should *not* mean merely doing things by or for yourself; it should also mean being rendered in control of how things are done to ameliorate your condition, by *others* as well.

Despite Everything! That’s the slogan we envision for the work of Andrea Dowdall, our brand new part-time social worker in this area. She’ll be acting as a kind of combination patient-advocate, home treatment facilitator, community educator, and

physician liaison. And we are attempting to further this aim in regard to MS patients *in spite of* the downsizing of specialized medical personnel cadres, *in spite of* incommensurately low reimbursements offered by many insurance systems, *in spite of* the redundant duplication and runaway cost of technology among competing localized medical institutions and the continuing scandalous shredding of the medical “safety net”, especially for those on Medical and Medicare. We intend to keep on pursuing this path, in fact, until the (often piously invoked but currently notoriously mutilated) safety net, and indeed the social contract itself, currently lying in ruins or ignored amidst the desolation of crumbling urban ghettos or abandoned “rustbelt” zones, becomes mended and restored in a less heartless time, presided over by less self-serving and self-aggrandizing men, women and institutions. And when far-sighted social and political action on behalf of *all*—not merely a small minority—of our citizens becomes once again the norm, rather than the exception, in this country, recalling not only our visionary beginnings as a nation, but foreshadowing our renewed, “rehabilitated” and *truly* “compassionate” (in *fact* as well as word!) future as well.

Lotte Marcus, PhD, with Alan R. Marcus