Options

Barry Corbet

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OPTIONS

SPINAL CORD INJURY AND THE FUTURE

BARRY CORBET

CHAPTER

ONE

NOTES ON THIS EDITION

A foreword to the unofficial 10th edition of Options

In 2023, when we set ourselves on the project of making Options available once again, the original text was long gone; the printer had been out of business for over a decade. So this edition was produced by scanning a copy of the 9th printing, followed by optical character recognition and assembly into the book you are looking at now.

Barry Corbet passed away in 2004, and is still much missed. Much has changed in the over 40 years since Options was written; some things have improved, others have not. But the words in this book, and the people portrayed within it, are as relevant and important as they were in 1980. We are happy to make Options available once again, and hope that it can help many others to understand the options that they have.

Jennifer Corbet, Jonathan Corbet, Michael Corbet, and Muffy Moore

For the curious: the scanning and processing of this work was done by the Corbet family, using the open-source SANE, ocrmypdf, Tesseract, and Unpaper utilities. The online version was processed using the Sphinx documentation system and the book theme.

CHAPTER
TWO

ACKNOWLEDGMENTS

The first acknowledgment must go to the Prevailing Times, which make it possible to be in a wheelchair and in the world simultaneously. It is the Swiss Reinsurance America Corporation which generously funded this book and its companion film, OUTSIDE, it is Ed Holden who convinced that corporation that the project was fundable and it is Doctor Robert R. Jackson who convinced Ed. Jake Kittle, friend, soundman, grip, bellman, procurer and vehicle-to-ground cameraman, held the overland journeys together. My eldest son, Jonathan, contributed the best of the sports photos. Craig Hospital was a wonderful home base to work from. Dr. Harry Hahn, Dr. Robert Menter, Bonnie Sims, Rick Harry, Scott Manley and Sam Andrews were invaluable resources there, as was Carolyn Mitchell at Good Samaritan, Nancy Becker Kennedy at Rancho los Amigos, Doctor Terry Carle at the Rehabilitation Institute of Chicago, Gerry Warren at the University of Washington School of Rehabilitation Medicine, Roberta Trieschmann, now at St. Jude, Judy Heumann at the Berkeley C.I.L. and Bruce Marquis at NSCIF. Most of all, I acknowledge, thank and salute the real authors of this book, the disabled people who fill its pages.

CHAPTER
THREE

FOREWORD

by John S. Young, MD
Director
National Spinal Cord Injury Data Research Center

What drives them? Whence comes their superhuman motivation and courage? What separates the Gimps and the Crips from the invalids? These sophomoric questions plagued me during the early years of my professional association with spinal cord injured persons. Only after years of peripheral involvement in their lives, including some deep friendships, did I realize that they are heroes, but only in the sense that all human beings have the capacity for heroism, particularly when they have no other choice. To this day, I have never ceased to be amazed at the ability of common, ordinary people to overcome adversity. The lives of the characters in this book testify that it isn't easy, but it can be done.

Certainly, *OPTIONS* is must reading for all spinal cord injured persons when the time comes to make their decision — some early, some late — "What am I going to do with the rest of my life?" The candid, pragmatic counsel of those who have gone before can be helpful.

Rehabilitation professionals, regardless of their level of expertise and experience, have a major handicap in understanding the desires and despairs of their "patients". *They haven't been there!* This book provides an intimate glimpse beneath the surface. This is where the action is. Rehabilitation is a people business and you have to know the territory.

OPTIONS is not only a book about the spinal cord injured. It deals with adversity and catastrophe; challenge, motivation and desires; and success. It is strongly recommended for all able bodied people. Sprinkled throughout the pages are philosophical pearls to be harvested by men and nations. The human race can and will survive catastrophy. People do it every day!

CHAPTER
FOUR

PREFACE

In 1968, I broke my back. The helicopter I was filming from unaccountably flew into a mountain.

I was a model patient. I was cooperative, cheerful and spoke confidently of the future. I left the hospital two months to the day after I had arrived, and everybody thought I was about the flashiest gimp in the history of the University of Colorado Medical Center. On the day I left, I got into my new hand-controlled Plymouth, picked up some groceries, went to a liquor store, met my parents at the airport (they'd flown in to celebrate my discharge, of course, not to help) and we all went to my new apartment to toast a new life. By then I was a little too tired to rejoice, but it was good. And I was glad for the help.

At three o'clock in the morning, my parents wheeled me back to the emergency room because my overworked stomach muscles had gone into spasm. Ignominious. Two months in, eight hours out. A shot of Demerol got me back to the apartment in time for breakfast.

I returned to work that week. This was a clear sign to the Department of Vocational Rehabilitation, Workers Compensation, the hospital staff and to me that I was fully rehabilitated. Remarkable. Instant recovery. A sixty-day wonder. Everybody loves a winner.

People still admire the way I have responded to my injury. They're sure I have all the answers. I now want to dispel that notion. While I cannot act on stage, tell a joke, mimic an accent or lie with conviction, I have fooled myself and others throughout these 12 years of paralysis. Fact is, I never did know what was going on, never did have the answers. Yes, the years have been OK. A few have been spectacularly good. One was spectacularly bad. Yes, there are easier ways to live. Yes, there has been compromise, but there have been great loves, great events, great moments. Yes, there has been great happiness and great unhappiness. But what characterizes those years is not happiness or unhappiness, but *change*. Really, the only thing I know for sure about those years is that *they sure were different*.

The point to get straight is that I'm not a joyful bundle of psychological acceptance, my middle name is not Everhappy, and I still don't have the answers.

That's why I got 54 other people to write this book for me. No one of them has the answers either, but collectively, they know a great deal. They know a lot of what you need to know, and I feel honored to be a conduit.

The hospital where I spent two months was not a specialized spinal cord injury unit, yet I received excellent care. The only thing lacking was exposure to other cord injuries, other people who shared my predicament and had experience in dealing with it. This didn't seem to be a problem at the time, and I was probably relieved not to have to confront other wheelers. It took me 10 years to realize that not only had I missed something important, but that I was still missing it. Some part of me was still broken, and was being steadfastly ignored. So in meeting and talking to the people in this book, I was searching for what I might have found a decade earlier had I allowed myself the company of experienced cord injuries. It became a journey of personal discovery, a game of identity hide-and-seek.

Once embarked upon this Giant Plagiarism, this picking of other brains, I found myself recognizing the experiences of others. The same things had happened to me, but had been stored somewhere below the surface of my normal recall. Bringing this body of experience into the light, into an area of availability and utility, has been enriching beyond all measure for me. I want you to share this experience so that you will not have to muck about in the wilderness for years, as I did, to acquire it by yourself. The wheel does not need to be re-invented, and why not take a free ride when offered?

CHAPTER

FIVE

PART 1: OBSERVATIONS AND ADVISORIES

5.1 A Story

Once, a person was severely injured. So severely, in fact, that the person suffered motor paralysis and the loss of many body functions normally taken for granted. It was soon discovered that complications such as bladder infections, contractures, pressure sores and spasticity were to be added to these trials. Furthermore, the injured person faced a lifetime in a wheelchair, experienced catastrophic disruption of personality, was extremely fearful of future relationships with family and friends, and had no means of support even though the torrent of hospital and doctor bills failed to reflect this fact. The institution to whose care this person was committed, however, provided all possible care and counsel and then, through a carefully conceived blend of incentive and disincentive, returned a changed person to a new world. The new world, viewed from a new wheelchair, was bewildering.

One dilemma was obvious: to cope or not to cope. To cope meant to work and play and live and love as if nothing had happened. But something *had* happened. Not to cope meant to refuse responsibility for personal health and welfare, to allow physical and psychological complications to bankrupt rehabilitation. Suicide was even considered, and nobody knew for sure if that was coping or not coping.

All the options seemed lousy.

We are the spinal cord injured. There are hundreds of thousands of us in America, and about ten thousand more every year. Although 82% of us are male, we come from all races, places, ages, occupations, educations and income brackets. We're all badly hurt, and many of us don't know what to do about living this way. It's a very good thing, therefore, that the world is full of people with injuries like ours who have coped, who are glad they are coping, and who give to the human race in full measure for what they take. This book is not only about these people; it is largely by them. This is their book, and it's for you.

5.2 A Very Brief Glossary of Terms and Abbreviations

AB, AB's, AB'd

Able bodied people . Not pejorative. Sub-types: TAB's, who are temporarily AB'd and SAB's, who are severely AB'd.

CIL

Center for Independent Living.

DVR

Division of Vocational Rehabilitation. The state "agency of last resort" which can provide a lot of help. Also called DR, VR and Voc Rehab. DVR is used here for consistency.

Level of Lesion

Locates spinal cord damage by reference to the adjacent bones of the vertebral column. Cervical lesions, the highest, generally cause dysfunction in upper and lower limbs. Thoracic and Lumbar lesions usually result in lower body paralysis. See *Loose Ends*.

NSCIF

The National Spinal Cord Injury Foundation. A national advocacy, research and information coalition. NSCIF is a merger of two former organizations, The National Paraplegia Foundation (NPF) and the New England Spinal Cord Injury Foundation (NESCIF).

Paraplegic

Or simply Para. Someone with paralysis of the lower limbs. Paraplegia, the condition, is sometimes used to include quadriplegia (e.g., NPF)..

PVA

Paralyzed Veterans of America. A national organization representing paralyzed veterans. Non-vets are welcomed.

Quadriplegic

Or Quad. In England, a tetraplegic. Someone with some paralysis of both upper and lower limbs.

Rehabilitation Act of 1973

Your bill of rights as a disabled person. Section 503 of this act contains the buzzwords Affirmative Action (employers with federal contracts must hire, promote and actively recruit disabled people) and Reasonable Accommodation (the job must be made accessible to you). Section 504 requires recipients of HEW monies such as hospitals, schools, many non-profit corporations and state and local agencies, not to discriminate against disabled people in employment, promotion and benefits.

SAR

Sexual Attitude Reassessment Seminar.

SCI, SCI’s, SCI’d

Spinal cord injury, spinal cord injuries, spinal cord injured.

SSDI

Social Security Disability Insurance.

SSI

Supplemental Security Income.

Wheelers

Currently, this seems to be the scrupulously polite term for anyone in a wheelchair. Also cripple, disabled or handicapped person and in*valid* (I always loved that one). They’re just words and have no power to hurt unless used with malice—an experience I’ve never had. Gimp and Crip are words used often and fondly by many of us. Chairperson, I’m sure, is also appropriate.

5.3 Expectations

5.3.1 Giveaway

I’d like to give you something, something really fine, and I don’t know how.

Listen: Something hard has happened to us both, and neither of us likes it. You’d have to be a little nutty *to* like it, despite the inexplicable fact that you’ll encounter lots of us who say our lives have been improved by our accidents. Strange. Still and all, I don’t think it takes much heavy thought for anyone who’s broken a back or neck to realize that big changes are coming and that nobody is giving anybody much choice in the matter.

What I want to give you is not a pep talk, sermon, complaint or even advice.

I don't want to give you a lot of how-to-do-it information about SCI, because others are more competent to do this and have done it better, as noted in the bibliography.

I don't want to project for you an image of yourself, because that would be presumptuous; and I know that right after I broke my back I wouldn't have identified much with the way I see myself now.

So what's to give? Here I am, a paraplegic charged with inspiring all you newcomers to a cheerful acceptance of wheelchairs, respirators, braces, catheters and cystometrograms, and I don't even *like* those things. A friend suggested I call this book THE JOY OF PARALYSIS.

I don't want to tell you that life will become easier, or the choices simpler, or that SCI is in any way beneficial to one's mental and physical health, because those things aren't true.

I do want to tell you that this monumental inconvenience can be lived through, lived with, loved with, laughed with, surmounted, shared, transcended and that —look out, here comes the pitch— YOU HAVE NOT BEEN DEPRIVED OF CHOICE.

You haven't been deprived of choice. You do have a lot of options. You can be OK if you choose to be OK. The future, however unfathomable, is yours. There are more than enough things you can do after a broken back or neck, and some of them you'll like so much that you'll be unable to contain the joy.

(I was a shy kid. I remember the first time I got drunk in a bar, loose enough to dance with an abandon my sober self denied me, then leaning against a urinal and thinking: There's too much fun here. I can't hold it all in. Later on, I thought the same thing skiing waist-deep powder snow in Jackson Hole, climbing mountains in Antarctica, floating in the arms of peyote back when it was still legal and kayaking after my accident. When your cup of rewards runneth over, it's a good time. My cup still runs over about as often as anyone else's. So will yours.)

I'm not religious. I'm not a saint. I'm not free of occasional depression, nor am I an incurable optimist. So 'tis not I offered up as example, but a farflung and chaotic scramble of wheelers, gimps, cripples and whatnots who have not only survived, but are happy they did.

It seems important to stress that these people were easy to find. For each of us profiled here, there are many thousands of others living equally vital lives. It should also be said that I don't expect you to identify fully with any of us. Wheelchairs don't make us alike. What's more, wheelchairs and braces don't look good to anyone until they bestow their gift of mobility. Until that event transpires, they are the stigmata of everything you don't want. And not everyone wants to be a lawyer, a jock, a city dweller, a parent, an employee or an employer. Everyone does want a life that brings satisfaction. While none of the people in this book may lead lives matching your goals, they do offer proof that lots of wheelers are meeting *their* goals.

5.3.2 Kid Stuff

I have lived two lives, both reasonably successful in the eyes of others, but, as lives will be when they're your own, both mixtures of success and defeat. One life preceded my accident, and the other follows. One is over, at the age of 31, and the other, in its adolescent stage at 43, is just a kid.

Like all adolescence, my second life is joyful and cranky, ecstatic and troubled. Quick to overreact, it jumps from extreme to extreme, is opinionated beyond words, and is subject to youthful exuberances and depressions which lack the maturity to coexist. In short, my balance, my perspective, my *sense of humor* are easily messed up by being too polarized, too black and white.

Shucks, is that all?

New things in life are usually welcome. Getting married, having children, moving into a new house, job or relationship

— they're not fun because they're easy. They're fun because they draw more substance from us, because they make us rise to new occasions and become larger people. So it should be with a second life. It's new and you're alive and the opportunity to jump in is rapidly approaching.

5.3.3 Change

> "I wasn't very damned happy about getting my neck broke!"
>
> —Don Rugg
>
> "I really didn't understand what happened to me, you know. I thought if I went to the hospital, they'd give me something and I'd get better."
>
> —Deanna Gonzales
>
> "The first doctor I asked, in Belgium, said I'd be walking in six months. The next one told me nine months. And I thought, Jeez, if it's going to be nine months, then I just don't want to live if I have to wait that long. So I stopped asking questions then, because I thought the next one would be even longer.
>
> "I knew, without any doubt in my mind, that I was gonna walk again, and nobody ever told me that I wasn't gonna walk again. I can't even pinpoint when I learned it was permanent. I know what the process was. It was when I was out at the University of Illinois and saw some of these people that had been five and ten years since their accidents, and these poor bastards weren't walking *yet*!"
>
> —Sharon Wilkin

5.4 Recovery and Rehabilitation

5.4.1 Some Frivolous Thoughts on a Very Serious Subject

Recovery is what we want.
Rehabilitation is what we get.

By now you know that surgeons can't repair spinal cords and that recovery is exceedingly rare. There have been isolated cases of hysterical paralysis cured through hypnosis, but no cases of traumatic paralysis being cured by anything. Your best shot is having an incomplete lesion, in which case nature sometimes squeaks through, a little at a time, and there is then some return of function. Complete functional return is very unlikely. So rehabilitation is the task at hand. Rehabilitation's job is to take your body *as it is* and to maximize your capabilities within recognized limitations.

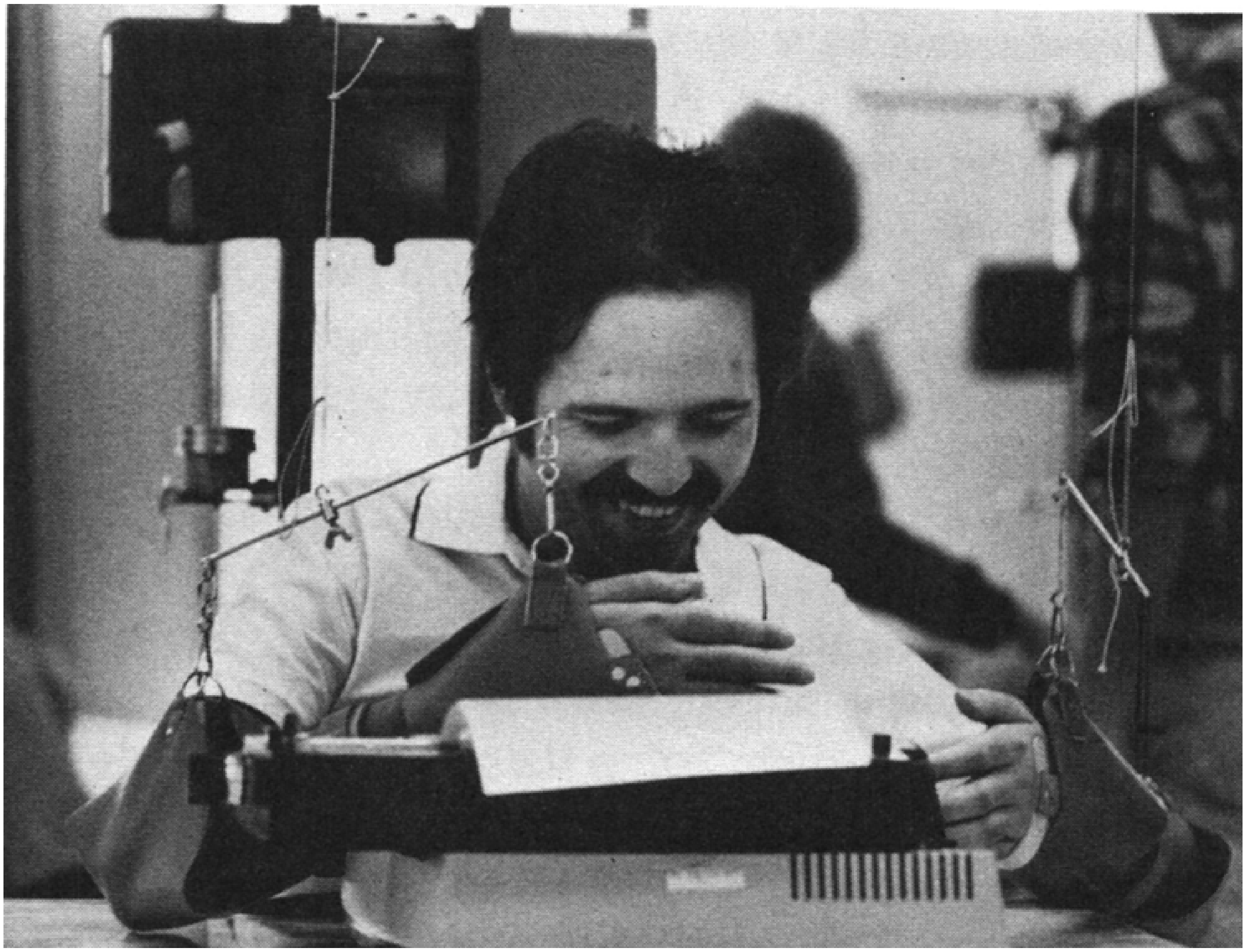
This is a difficult acknowledgment. Rehabilitation seems only second best, which is exactly what it is. To fully accept rehabilitation, for most of us, is to effectively abandon recovery. Rehabilitation can give you strength, re-education, skills and real improvement, but no cure. Many people find this an easy bridge to cross, and a few find it so upsetting that they temporarily want out of the game.

Your body: love it or leave it? The contemplation of suicide, as a singular experience, is pretty common and is not at all the same thing as being suicidal. It's a valid question, not one to hide or be ashamed of, and it's a question which should be dealt with very directly. Don't delay, because suicidal thoughts are crummy companions on lonely nights. Ask yourself whether you want to live or die. Ask out loud if necessary, but get the question out in the open and out of your mind. While you're at it, ask yourself if you have enough information yet to make an intelligent decision.

Many SCI's have told me that they once contemplated suicide, usually soon after their accidents. They were all, of course, still alive when I met them. In fact, while provable suicide is not unknown in SCI, it is uncommon. But self-destructive refusal by the individual to take responsibility for his or her own health is quite common. (If you want percentages and numbers, see Roberta Trieschmann's book, cited in the bibliography.) Somehow, malign neglect seems like a particularly wishy-washy way to make a statement.

And then, suicide has disadvantages that exceed even those of SCI. You're in a bind, and the only way to proceed *is* to proceed.

If we can't get off our asses to do something, then the next best thing is to get *on* our asses and do something. Screw it; just do it. Get up, get started, get going. You can always kill yourself later. Then, when you've picked up some new skills, you'll know enough about what you *can* do that your curiosity might be aroused. So give rehabilitation a try, because it's what you need. And refer to the next chapter to see if you're in the right place to get it.



5.4.2 Is This the Right Place?

Large general hospitals, where most people land after any kind of major injury, are magnificently equipped and staffed to handle the acute phases of pretty much any trauma. What they tend to be less good at is the extended *specialized* care and rehabilitation services required by SCI.

All SCI treatment is not created equal. It varies from excellent to atrocious. Recognizing this fact, the National Rehabilitation Act of 1973 designated 11 Regional Spinal Cord Injury Centers, some of which have satellite units. The number of centers has now grown to 15. If you are in one of these centers, you're extremely fortunate. If you're not, and over 85% of new injuries are not, then you need some criteria for judging the quality of the care you are getting. It may be excellent, but you need to know if it's not.

You *need* medical and nursing personnel with extensive experience in the management of SCI. Seeing three or four

SCI's a year is not adequate qualification.

You *need* Whole Body Care. Most hospitals are collections of diverse services which surgerize, repair pressure sores and treat urinary infections, contractures, pulmonary complications and troubled psyches only after these needs have been created by incomplete preventive medical care. A good SCI facility will assign one doctor who specializes in SCI (not neurosurgery) to coordinate the work of the rest of the staff. That is, he will act as an advocate for your whole body, not just your individual parts. He, with your diligent cooperation, is your insurance against preventable complications.

You *need* the company and counsel of people with injuries similar to yours. Unfortunately, this is your most alienable right. In a large city hospital, you'll be lucky to find three or four other SCI's, and you'll probably only see them going the other direction down a hallway on a gurney. In any SCI Center, there will be dozens of other SCI's, and you'll spend most of every day with them. This might sound depressing to you. It's not. It's creative and invigorating. In addition, there is a constant flow of old grads returning for occasional reevaluation. The sheer quantity of information, the multitude of coping ideas and solutions and the ease of communication when all present have similar concerns are truly galvanizing. These people are far and away your best advisors and your best access to information.

You *need* therapists and counselors who are specifically trained in SCI, and the facilities (gym, weights, mats, bars, bracing, adaptive devices, recreation facilities, etc.) for effecting your rehabilitation.

A few general hospitals can provide you with all these things, and well. So can a number of rehabilitation centers outside of designated Regional SCI Centers. See how you feel about the considerations below, then make a decision. Remember that SCI Centers can't work miracles. They can no more repair spinal cords than any other hospital. They can get you up and moving, and that is the present need.

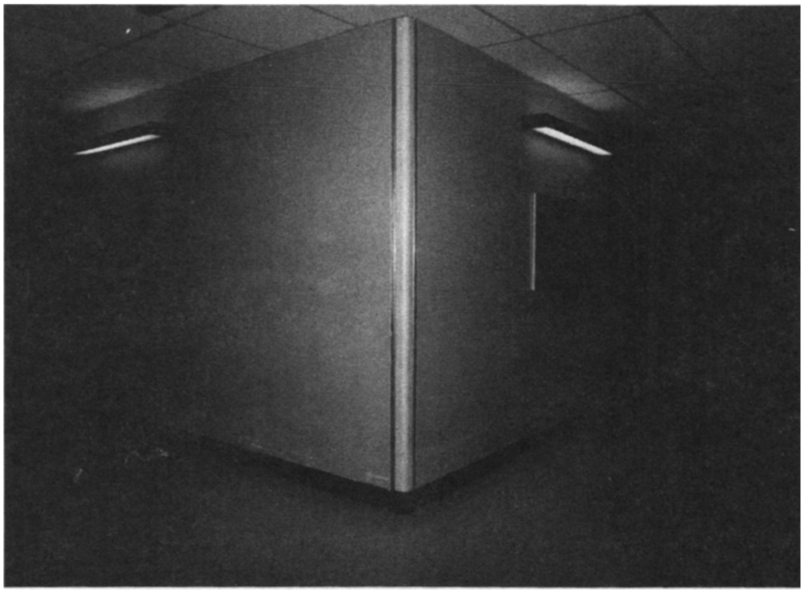
- If you're expending most of your time and energy fighting recurrent pressure sores or bladder infections, you're in the wrong place.
- If you can't get frank and specific answers to your questions about emptying your bladder, moving your bowels, or your sexual or occupational expectations, you're in the wrong place. For that matter, you're in the wrong place if those questions are difficult to ask.
- If all or most of your time is spent in your room, even after the acute phase has passed, or if you are moved only once daily for an hour in a physical therapy cubicle, you're in the wrong place.
- If you have the feeling you're being hidden, you're in the wrong place.
- If you're not being taught to become a genuine expert, *the* expert, on all aspects of your own health, you're in the wrong place.

Treat yourself right. Give yourself every chance. It behooves you to get to a good rehabilitation facility to be kind to yourself, and it behooves your insurance company or financial aid source to expedite your transfer because *better care is cheaper care*. That's because you'll be out of rehabilitation faster and healthier and better equipped to stay out. Don't let yourself be victimized by incomplete knowledge of your condition and of your abilities. And most of all, don't allow yourself to be filed away in a neurological ward or nursing home without examining all the alternatives.

> "Keep active, keep trying things, and don't find the answer. Don't let someone tell you you've found the answer, because if you do, by God, it's gonna be an institution or it's gonna be a nursing home or it's gonna be invalidism in your own house. Because that's the answer, statistically, that most paraplegics and quadriplegics have and get. Keep doing things, keep making mistakes, and don't follow all the instructions because you will not find new behavior that way. And if you don't find new ways of behaving, you aren't going to find new reinforcements. You're not gonna get paid off in novel experiences, so your life is gonna become very constricted. I guess what I'm trying to say is that if you find yourself in this kind of constricted life, and you don't want it, then keep wigglin', keep movin', stay alive."
>
> —George Hohmann

5.4.3 Corners

Let's say there exists a corner which you have to turn, and after that you're home free. Not that you'll take up pole-vaulting again, but just that your life will settle out into a reasonable and workable thing once you've turned the corner. Maybe the corner is the point at which you concern yourself more with the activity and less with the anxiety of living.



Corners need some examination—they're potentially tricky. Like, is turning the corner just a defeatist acceptance of the unacceptable? An act of faith, which is fine if you're of the faithful? Is it the decision to live, as opposed to only exist? It might be scary around the corner, then again, maybe there's a risk of fooling yourself into thinking you're OK because you want so badly to see around that corner. Perhaps the staff has programmed you with insidious intervention strategies and behavior modification lurks behind every smile of encouragement.

Or perhaps you *see* something. A goal, a real reward out there that's realizable and worth working toward. If so, if you have that awareness of a desirable objective and sense that you can influence the odds of achieving it, then you *are* home free. That's the corner.

Goals come in two forms. There are take-one-day-at-a-time goals which sustain and amuse us in the absence of passion. Business as usual; busy as hell. And there are the goals we perceive way out there in the future-murk which we will work toward with consuming passion. The identification of realistic goals is the keystone of all rehabilitation.

No goals; no home free corner. No free lunch. An immediate goal might be to find a goal…

But perhaps you feel that, personally, you're sort of short on goals. Sort of, excuse me, crippled by apathy. Today, tomorrow and forever. That's understandable, but it leaves you only the past to deal with, and that's going to get boring.

So pick a goal. Manufacture one. Make a phone call. Make the night nurse laugh. Put cranberry juice in your leg bag without drinking it first. Or, what the hell, do a transfer just to please someone. Have a voluntary. Take a therapist to lunch. Pick anything you haven't been doing but can do, then do it. Little successes feel good and spawn new goals which have real heart to them. Achieved goals have a snowballing effect. And when you become President, remember that you once thought getting dressed or holding a fork was a significant challenge.

And if you still can't scratch up any enticing goals, it's probably because you're not aware yet of the options available to you once you start hustling. Most of the people in this book had the same problem. They can open doors for you. You don't have to go through the doors, but they do ease the passage if you're bumping into walls.

5.4.4 Lighting a Fire

> “*Better to light one candle than to curse the darkness.*”
>
> “Motivation is within each individual. If it can be found, if a person can find it by himself, with assistance, with some counseling, with whatever is necessary, that is going to be the trigger that moves them towards a goal, towards a success and a feeling of satisfaction.”
>
> —Gene Tchida
>
> “Looking back on it now (after 23 years!), I probably was too eager to accept DVR’s answers of me being severely disabled and not becoming independent. But when I look back, I can see that the *only* way for me to get out of the four walls I was looking at was for me to make the effort. And finally, at long last, I learned this lesson.”
>
> —Bob McGinty
>
> “A healthy skepticism is what you need, because you are unique and the way you recover and the way you will adapt will be totally different from the way anybody else does. And if you allow anyone to define you, you allow them to deprive you of some of those abilities that you might have, that you more than likely do have. It’s just incredible that people let other people define them.”
>
> —John Galland
>
> “If the person is accomplishment-oriented, they will do it their injury be damned. Regardless. If they’re not accomplishment-oriented, their disability will become the reason for not accomplishing.”
>
> —Elmer Bartels
>
> “I think people have to first create in themselves a force or a will to do something different, and then create a little person behind them to push them through it. And it can be done. People can do whatever they want to do. It’s just a matter of focussing your mind on it and going with it.”
>
> —Jim Albert
>
> “I became very motivated and directed. And I think that the two biggest things that contributed to that was that I went right back into what I was doing before, and I didn’t lower my expectations.”
>
> —Nancy Becker Kennedy
>
> “The idea is to expand choices, to give people all the choices they want. Then you’re no longer handicapped.”
>
> —Steve Epstein
>
> “When I think about all the things I can do and can’t do, it seems to me that there’s an awful lot of things left *to* do.”
>
> —W. Mitchell

5.4.5 More on Rehabilitation…

Basic rehabilitation is a drag. It teaches you what you learned in the first four years of life—mobility, personal hygiene, avoidance of hazards, muscle development and other pretty unoriginal stuff. The best thing going for it is that not doing it is much worse than doing it.

But that’s just Rehab 101. If you’re in a good place, you can attend a Sexual Attitude Reassessment seminar (sounds ominous, but they show you lots of dirty movies), learn to drive a car (takes 10 minutes if you’ve driven before — instant freedom!), join group sessions on relationships, self-image, self-presentation, or whatever else needs discussion, receive vocational counseling and training, learn about money sources, get in some recreation and maybe get out on the town and mix with some normies. (They're pretty weird, but you get used to them.) Lots of good information here, and even some good fun. Enter rehabilitation with a full heart.

Remember that the genuine aim of rehabilitation is to achieve your goals. Tell them what you want to accomplish, show them that you're willing to work, and they'll literally give you the world. And consider that the various therapists—occupational, physical, speech, GU, sexual and recreational—are specialists and can't be expected to intuit your overall needs. Make it your responsibility to bring their skills together to achieve your goal.

And what's your goal? To *escape*, of course.

5.4.6 The Great Escape

It's a little like getting out of jail, except that the staff wants you outside instead of inside. So line up your shots. Acquire the physical skills to be as independent as your injury allows. Acquire the social skills to deal with other people. Acquire an attendant, if you need one, or perhaps a job, a car, an education, a lover or a place to live. Then figure out the realities of paying for these things. Learn all you can about the care and maintenance of your body and mind. And understand fully that once you do escape, your rehabilitation will begin in earnest.

If you're nervous about the escape, inquire about the equivalent of minimum security lockup. Many SCI centers can provide out-patient apartments which still have access to hospital services. Occupancy is temporary, but can ease the transition.

But don't hang around any longer than you have to. Institutionalization is addictive. Move on out, because there's a big world out there, and it's just as ready for you as you are for it.

5.4.7 Postpartum Blues

It's only fair to warn you that many of us have found the first weeks or months after the escape to be the most difficult ones of all. Hard times. While the institution was toilet training you and teaching you mobility, it was also becoming your sheltering mother who loved you in spite of your flaws, real or imagined. That comfortable shelter can be difficult to abandon for the ragged, jagged edges of real life.

The best preparation is simply to know ahead of time that there might be a low spell, and to know that, if it does occur, it will wear itself out. People tend to let themselves be surprised by post-institutional depression, which makes them more vulnerable than they need to be. Better to be forewarned. If it happens, it happens. It will end after awhile. If it doesn't happen, rejoice but do not gloat. Virtually everyone has *some* down period after a major injury. And when you're down, it's easy to think that all of your days will be this way. Always. They won't. The blues will depart like a case of the mumps.

And with this caution and this encouragement, and with only occasional interruptions, I give you into the hands of the real and true authors of this book.

CHAPTER

SIX

PART 2: INTERVIEWS AND INTERMISSIONS

6.1 The Authors

Here are some lives.

It would be a disservice to present the people in this book as lived-happily-ever-after stories, for whose life is like that? We not only all have problems; we all need problems. Why else would we accept recreational and vocational challenges or fall in love? These things complicate and add difficulty to our lives, but we choose them willingly because they also add richness. So this book is not an effort to portray anyone's life as relentlessly marvelous. These are lives with *enough* joy.

Who can ask for more? Who can be satisfied with less?

There are no Perfect Beings in this book. Compulsive Overdrive is only a temporary condition for even the most committed of overachievers, and it would be a mistake to think you should do as they have done or to compare your progress of weeks and months with theirs of years and decades. There's nobody superhuman here: just people who, quickly or slowly, incisively or haltingly, identified and then did what they *needed* to do.

Is there more to achieve than this?

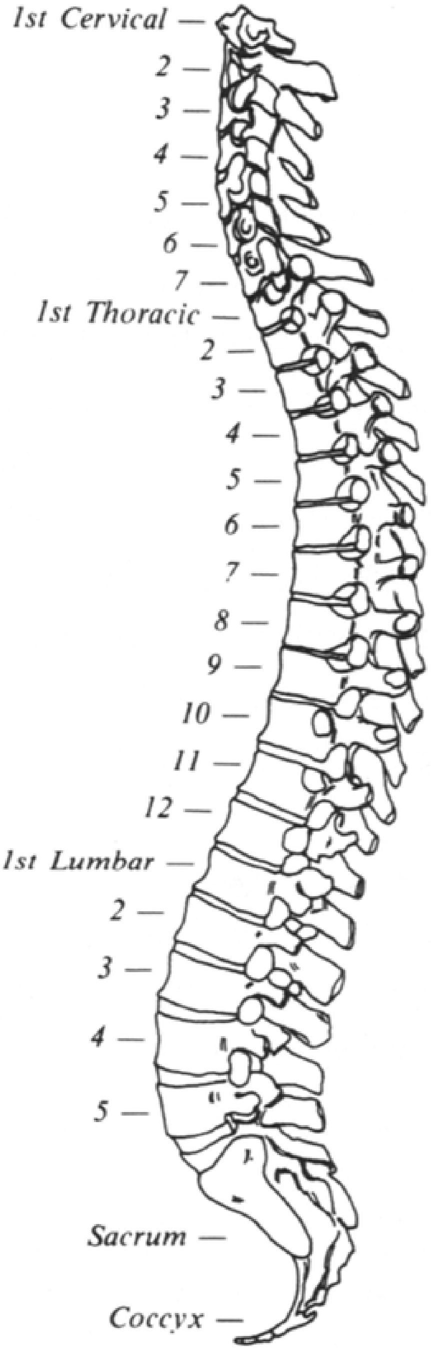
There will be statements about change. They are valuable as attitudinal indicators, but how does a 16-year old know if sex is better or worse since the accident, or if relationships are more or less complete, more or less satisfying? How does a para who adopts or conceives a child know if able bodied parenthood would have been more or less fulfilling? How can a quad who becomes a lawyer know if able bodied success would have been sweeter? We mature in spite of ourselves, with or without SCI, and change comes to us all. So this book is not an attempt to reduce or mitigate change, but an invitation to *welcome* change.

How else could we look forward to our days?

And, in these lives, there will be found some fine filament of sorrow. If these stories were of parents who had lost children, or of amputees, there would be the sorrow of a lost child or a lost limb. We have lost a neurological connection, and there is every reason to acknowledge the loss. So we have not escaped the sorrow, but have refused to let the fact of injury interfere with the fullness of life.

What else is there to do, and who could do better?

6.1.1 Loose Ends



Hospitals and Rehabilitation Centers: Fifty years ago, all institutions were inadequate for the spinal cord injured and all care was primitive. Times have changed since then, and good care and treatment can now be found. As in any long learning process, mistakes were inevitably made. Even today's state-of-the-art SCI centers are responsible for a few of yesterday's horror stories, so it seems clear that institutions should be judged more on their present works and less on their past shortcomings. For this reason, I have protected many institutions from their own histories by leaving them nameless. But nameless may not be blameless. Bad care is still very easy to find, and this book attempts to help you to distinguish it from good care.

Level of Lesion: Any hospital can provide a chart which locates the spinal segments. While injury levels are given in all of the profiles in this book for rough comparative purposes, it should be understood that two people with nearly identical injuries will likely have very different consequences. There is no sacred level of performance that every C5 injury must attain other than to do as much as is realistically possible and useful. While the accomplishments of super-achievers are often laid to force of character or divine intervention, perhaps properly, these accomplishments may also reflect neurological quirks.

The Film: The interviews for this book and the location shooting for its companion film, OUTSIDE, took place simultaneously. Hence the occasional references to cameras, recorders and lights.

The Profiles: Descriptions designed to allow comparisons (kind of injury, level, date and age at onset, social background, post-injury history) require some redundancy. It is necessary for me to repeat and for you to forgive. And to sift through the profiles for those that seem comfortably close to home. This is a smorgasbord of sorts, and you are invited to pick and choose. It may require time, a little living with an injury, before some of the interviews which follow have full meaning, or even make any sense. Take your time and make friends with them as they seem helpful. They're good people to meet at the right time.

6.2 Lives I

6.2.1 Fred Cheshire

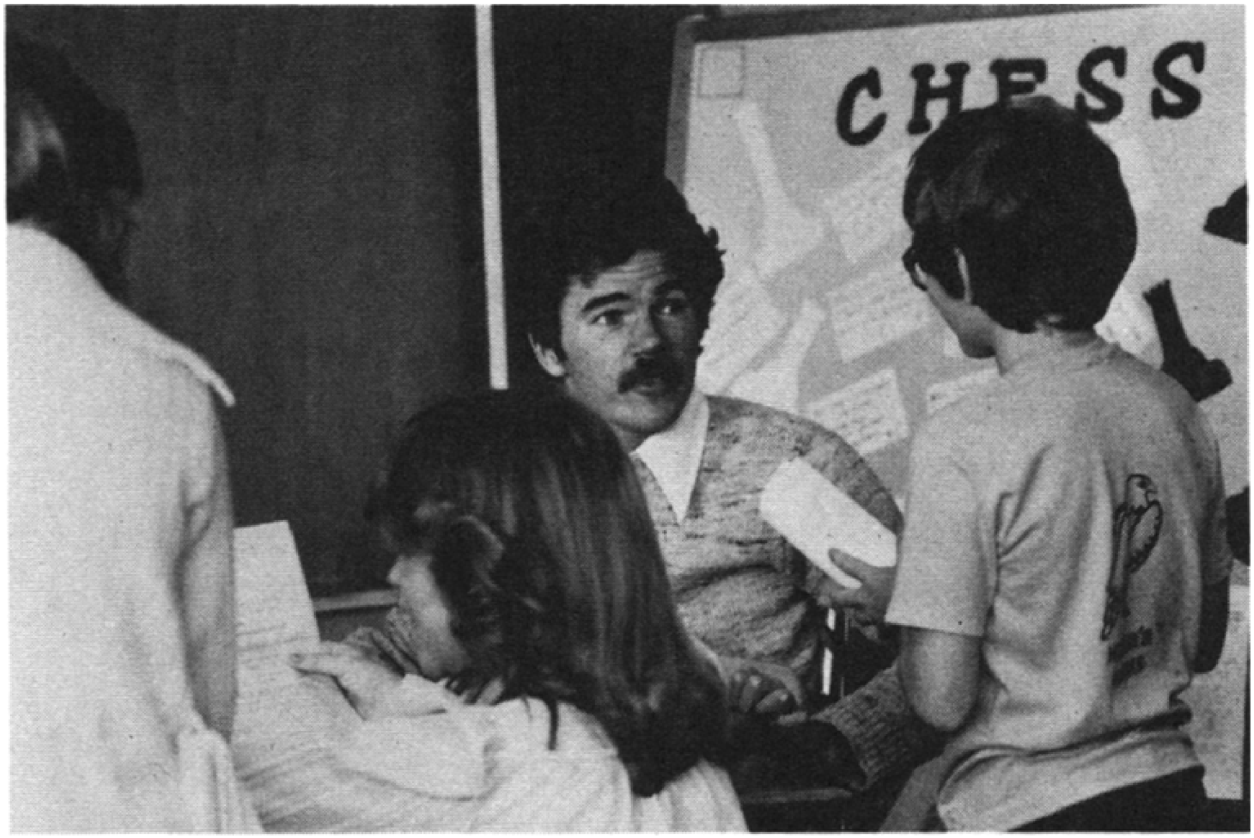
Fred was 31 years old in 1977, and doing fine. He'd survived 10 years of marriage and a recent divorce, eight years of school teaching, and had a job with unheard-of freedom teaching unusually gifted elementary school students. He was also coaching archery and his kids were getting to the Nationals year after year. He had a new girl friend, Debbie, who was with him the day he hit his head on the bottom of a swimming pool and became a C5,6 quadriplegic. He lay on the pool floor, fully conscious, until Debbie fished him out.

In 1979, Fred's life has changed. He's still got that incredible job, he's still sending archers to the Nationals (one of his protegés recently won the Championship of the Americas in Brazil), but now he and Debbie are getting married in August and he's working on his doctorate. Now he values time so much that he's a little like an electron—he appears to zoom from place to place without traversing the intervening distances.

Fred was initially convinced that his teaching career was over. That was before the flood of visiting colleagues, administrators, and, especially, students, all of whom wanted him back. They ramped the school, reserved a parking space, and students from dozens of neighborhood schools raised much of the money needed to buy a van. I don't think he really had much of a choice: "When I got back, I looked at them funny, they looked at me funny, probably for a day, and after that everyone accepted that they had a wheelchair person on campus." So much for the dread reintegration blues.

Fred's accident was in June. He started teaching one day a week in November, while still living at Good Samaritan Hospital, and within eight months was working full-time. Speedy.

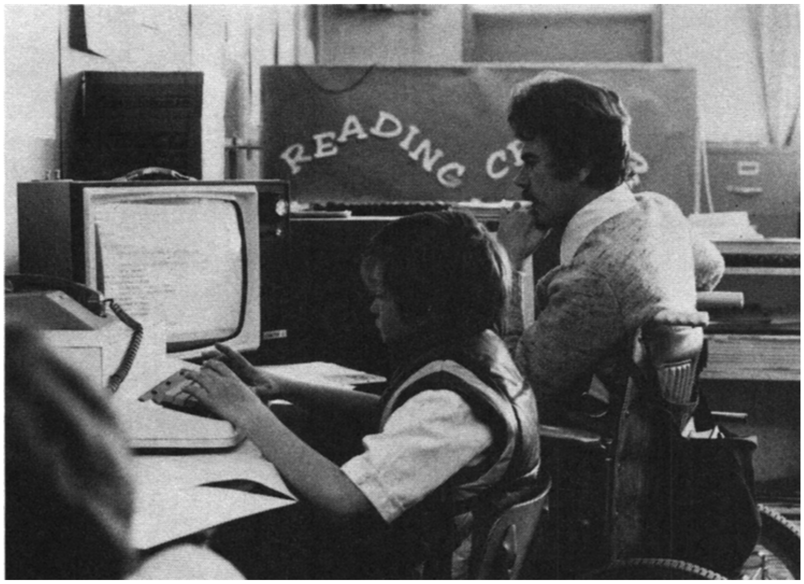
It's easy to see why he was in a hurry to go back to work. The kids all have theoretical IQ's checking out between 130 and 160, and it's a constant multidimensional chess game to keep up with them. Fred likes the game: "It's almost an escape to work with my students. That's where I get my reinforcement —from working with students and working with people, fitting myself into an environment where I feel productive."



There's a fantastic scope to what Fred does. He can coach one student through a simulated whale migration program on one of his two classrooom computer terminals, simultaneously offer suggestions to another student on an algebraic logic problem, listen to yet another describe an independent study project, then bring them all together to practice archery. He has an amazing capacity to direct full attention to a multitude of activities and levels at once. His classroom is a very busy place.

Consequently, his classroom is a madhouse. Or it would be if Fred weren't so good about organizing his kids so that things get done easily and efficiently. Being able to walk might actually slow him down, for he'd lose some of his highly developed knack for delegation. As it is, the room is disorderly in that everyone in it is doing something different. It's rowdy, because the students feel free to interrupt Fred whenever they need his help. And it's one of the most creative learning environments I've ever seen, because the kids have chosen their own projects and are aggressively learning as fast and as hard and as much as they can about what they want to study.

Fred suggests a similar approach to learning about SCI: "Learn everything about wheelchairs, leg bags, how people are going to be talking to you — anything that goes on around you, ask *why*. Ask why it's happening and understand it. Don't ignore a thing. Learn everything you can, because it's going to make your survival a more positive experience when you get out into the world."



"Talk to people a lot; don't get engrossed in your own mind. One day you're going to feel up on something, and another day you're going to feel down on something. One day you're determined that you're going to do one thing with your life, and the next day it's going to be another thing. And that's fine. That's natural. Go through all those changes. Play with a lot of different ideas until you find what's comfortable."

Fred seems to have found what's comfortable. I asked him if he ever was subject to depression, and he said that he'd been swamped with so much positive input from people, his community and his church, that he hadn't ever been depressed. And after a moment's thought: "I don't think I've ever had the *time* to get emotionally down."

6.2.2 Gwen Ruona

"I like dealing with people. I like the contact with all types of people and it's like an education, constantly, because you have first contact with everything that happens, that comes in."

It's a very good thing that Gwen likes people, because she sees and talks to more of them in an hour than I can handle in a month. She works the switchboard at a large television station in Denver.

Here's a tape transcript:

- Good afternoon, KOA. Yes you may. One moment please.
- Good afternoon, KOA. Dick Clark's Live Wednesday? It'll be on from nine til ten on the thirteenth of December. You're welcome.
- Good afternoon, KOA. Wednesday Night at the Movies? From seven til nine will be the New Adventures of Heidi. Thank you, bye-bye.
- Good afternoon, KOA. That's right, we have taken it off the air completely because they haven't been paying their bills. No, what's being scheduled in its place is 700 Club; that's also a religious program. Uh huh, lot of people feel the same way. OK? Bye.
- Good afternoon, KOA. Pictures of the cartoons? OK, let me put you up to TV Promotion; they should be able to help you.
- Good afternoon, KOA. I'll put you through.
- Good afternoon, KOA. We'll have a Flintstone Christmas Special from seven til eight on the eleventh of December. Uh huh, thank you.

Total transcript time: one minute and 15 seconds out of her eight-hour day. During the same span of time she has buzzed 10 people through the security door, handed messages to several and communicated non-verbally with all. Gwen is no switchboard operator; she's an organizer, a choreographer, a catalyst, a power broker. She *runs* the place.

Here's Gwen conducting:

Vital statistics: Car accident, 1974, T5 para.

"I just laid around and collected Social Security, trying to get myself together to see what I really wanted." There was a year's gap between her accident and her job at KOA which she feels was the most depressing time of her life. But…

"When my accident happened, I was 21 and I'd done some living. My life wasn't all that easy, and I'd been through a lot of ups and downs. But I always picked myself up anyway, so when the accident happened it didn't bother me.

"It's amazing that there are a lot of people willing to help you, and really *want* to help you, so there is no excuse that I can't find help or someone's not willing to help me out, because there always seems to be somebody around that would want to do something for you."

While she is often frustrated by her wheelchair, she says she is *never* embarrassed by it. And I believe her. She's got one of those invisible wheelchairs, the kind you can't see because the person in it doesn't know it's there. She emanates an aura of pure communication, and it works.

Gwen lives in a totally accessible apartment with a boyfriend she met at work: "We clicked off, he just moved in, and that was that."

And sex? "There's always someone out there for everybody. And there's so many different ways. If you have any imagination at all, you can make it successful."

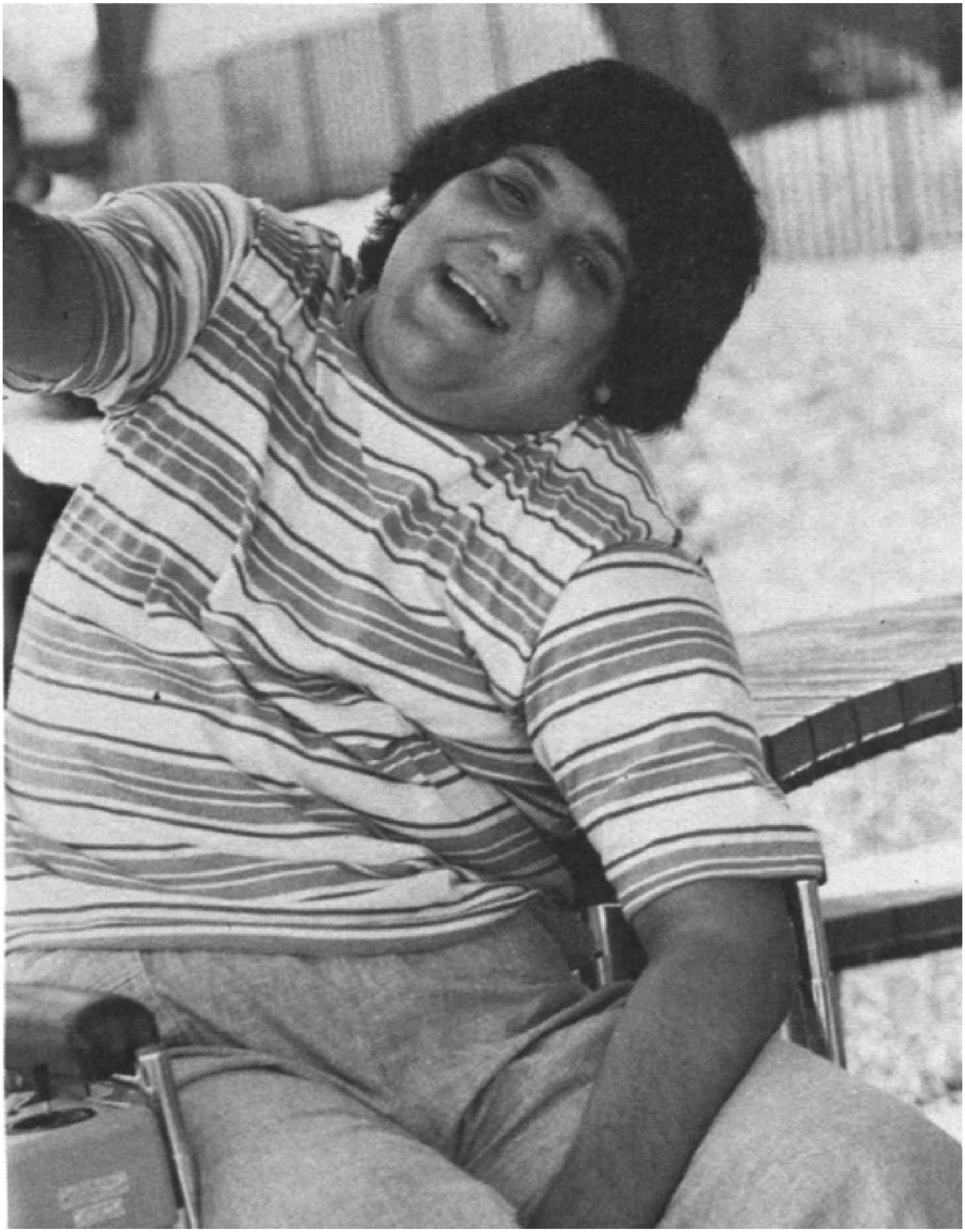
Gwen sees herself as a sort of mother confessor, an inspiring example and a good listener who identifies with other people's problems. Most of the people she buzzed through the security door looked as if they wanted to stop for advice, consolation or a good laugh. I felt that had I not been there, they would have.

Her aspirations? She wants to do voice-over for commercials and public service announcements, and perhaps eventually produce documentaries. She has the qualifications, but is frustrated by the current inaccessability of the announcer's control room. That can be corrected, but when it happens KOA will be very hard pressed to find a halfway competent benevolent dictator to run their main show as well as Gwen Ruona.

6.2.3 Stephen Epstein

“Two weeks ago, I hopped on a plane at nine o’clock in the morning in Miami, flew to Denver, got in at 12 o’clock, got an Ambocab to Craig (Hospital), sat in on a medical conference, met the parents and the kid who was injured in the case, caught the 6:45 back to Miami, and was back home at one in the morning.”

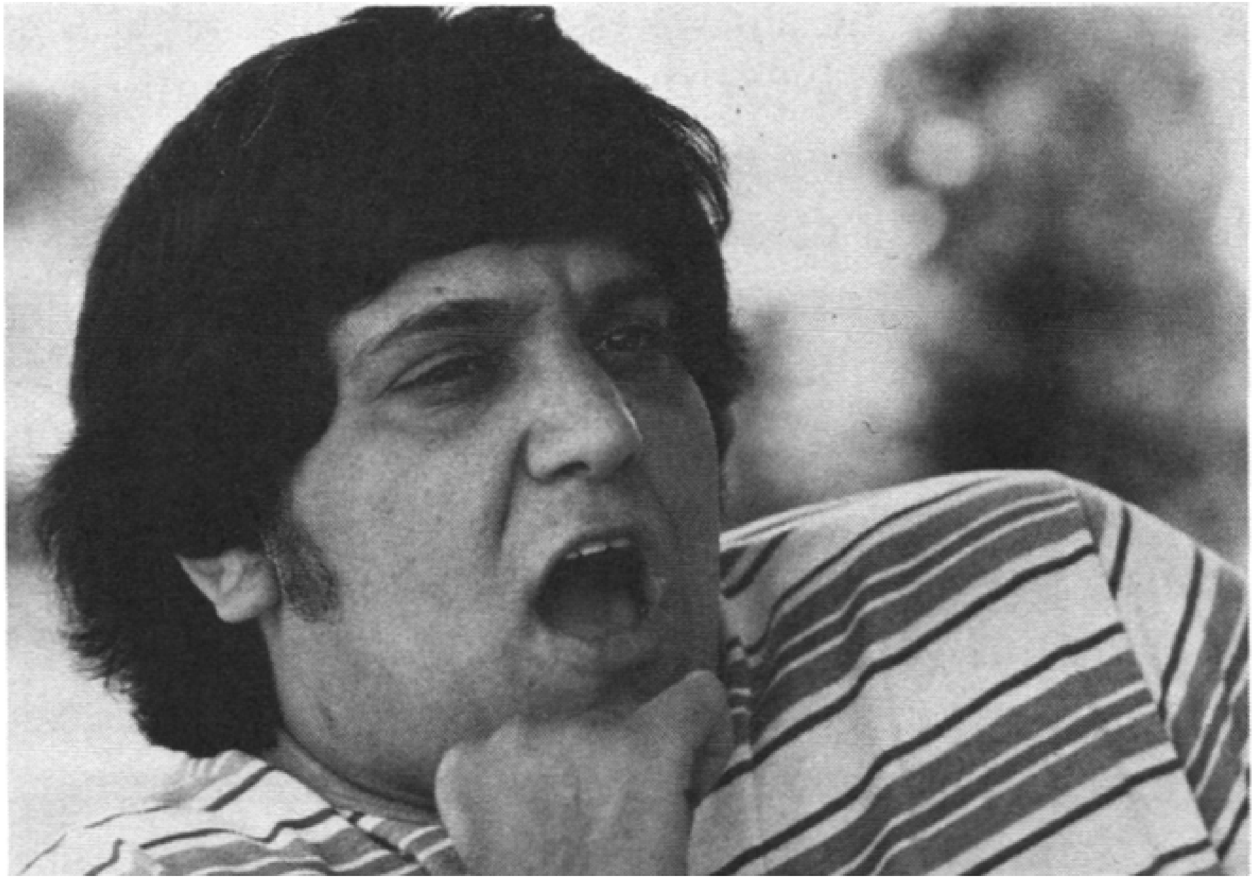
A day in the life of Steve Epstein. Four days later, he and his wife drove their van back to Denver. He’s just finished his re-evaluation and now we’re talking.



“I once cut school and went to fly a kite with my wife. We were going down this embankment at Golden Gate Park, and I hit a pothole and went flying. Down the hill, about 75 feet, I went flying out of the chair, chair went flying, batteries went flying, and the whole time I’m rolling I’m going, I’m OK! I’m OK! I’m OK! I’m OK! I ended up at the bottom with the batteries on top of me, the wheelchair on top me; Gail couldn't get down to where I was. We got to the doctor, Doctor Traynor says Don't worry if you broke your back; you're a quad anyway. They checked my leg; I didn't break it. We plugged the chair together; it worked. And the grass stains came out of my pants."

This guy's like every stand-up comic you ever saw, except, of course, he doesn't. He's a rolling mouth, a man totally lacking a sense of embarrassment, an invulnerable self-image moving out on wheels. He's great. He's an attorney ("I'm not a lawyer; lawyers hurt people"). He's litigious, which is to say he has a sue-the-sons-of-bitches attitude. He's a crusader for gimp rights. He's Saint Stephen. He's funny, angry, compassionate and speedy. He's one of those people you'd rather let talk than talk about.

Accident: Diving, upstate New York, 1968. Sixteen years old. "They pulled me out, punched me in the face and got me breathing. They said, You're OK, you're only paralyzed. There was a doctor on the scene. He stuck a pin in me, he said C6, and he was right. I'm a C6 quad."



Rehabilitation: Twenty-two months (!) at a center in New York state. Bad. He received the kind of treatment he's now fighting. High School and rehab completed simultaneously.

Schooling: Undergraduate degree partly funded by DVR. Graduated, met and married Gail, and went to law school in San Francisco. He paid for his own post-graduate schooling by taking out a loan ("I didn't want to deal with DVR at all, it wasn't worth it").

Why law? Because he'd met Sidney Golman, an attorney and pioneer in getting cord injuries to good care, and Doctor Robert Jackson, medical director (now Emeritus) at Craig, who provided most of that care. Together, they gave Steve a sense of mission which burns brightly today. And Sid promised him a job when he passed the bar exam.

Steve passed, worked for Sid for a year, then started his own practice in Miami. He works in Rehabilitation Medicine, which, for an attorney, means insurance claims, no-fault, workers compensation, liability cases and medical management. Not too surprisingly, he specializes in SCI and brain damage. And to it all he brings a sense of compassion for the injured party and a sense of outrage at the medical care doled out by most hospitals. ("It's a violation of your body.

It’s rape.”) He’s respected by gimps and insurors alike, because he shows them both that what’s good for the gimp is sauce for the insurance company.

Here’s a sample of what Steve thinks about options for the severely disabled: “We put people in all these weird stereotypes, and one of them is that all gimps should go to college because the only way you’re going to get back into things is to do that. I just don’t believe it. I think the key to everything is choices. I think the people have to make choices, and not the insurance carrier, not the DVR, and not the person who’s managing the claim. The real purpose of rehabilitation, of managing cases and bringing people together, is to give them all the choices and let them make the decisions. There’s so many people out there making choices for other people who are disabled, it’s ridiculous. The only choices belong to the person who’s disabled, the injured party — being able to decide that you want to do nothing, you want to do something, you want to do everything. That’s his choice. But the point is that most of the time, when a decision is made, it’s made because there’s no alternative. And that’s what I resent.”

On motivation: “Most people fall in the middle; their lives weren’t so great or so bad when they got hurt, and they’ve gotta go reconstruct. The problem is, you need the tools, and people are very rarely given the tools. You see guys doing things like intermittent catheterization four times a day, who take three or four hours to do bowel programs. How the hell can you have a life if it takes you three hours to crap? It’s crazy. How can you motivate somebody who doesn’t even know what’s available to him? The answer is information and choices. Then you’re no longer disabled. Then people will be a lot more motivated.”

He feels that some of us who flail about more than necessary are victims of our own attitudes: “They perceive that their life or their self has ended. My self hasn’t ended. I’m Steve Epstein. I’m gonna be Steve Epstein until the day I die, and that’s not gonna change because I happen to be a C6 quad.”

He’d like to see SCI’s shuck what he calls their I’m-not-gonna-walk dance, and abandon the endless search for recovery, waiting for a complete return to normalcy. “There’s normalcy here in the wheelchair, and that’s what I think a lot of people miss. SCI is really a minor thing. I know people think you’re crazy when you say that, but it’s true. When you have your mind left, when you can still create, think, do things that are great, that’s what it’s all about. Hell, I’m all here. The only thing is I can’t walk. I roll places instead of walking. Sometimes I roll faster than people can walk. Big deal!”

Attitudinal barriers: How do you change them? “Easy. Just go out and be people. Be yourself. Travel, go shopping, mix, talk, live. Live life, that’s the real key. I mean, how many people just exist? Just go out and be yourself.”

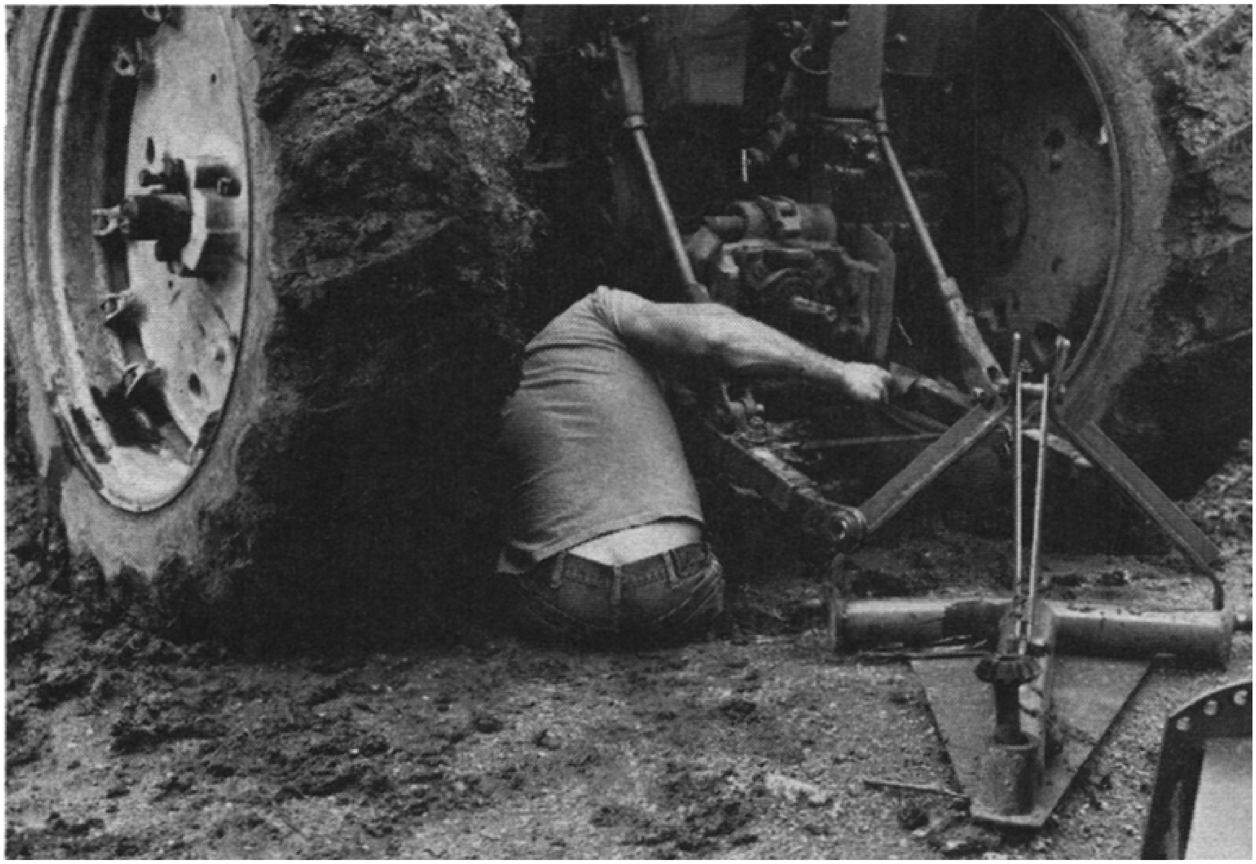
Parting shot, offered with the disclaimer that, in Steve’s lexicon, “nigger” is a political word, not an ethnic one: “Gimps are the last, the final and the only niggers in our society. We are because in our own definition we allow ourselves to be hidden, we hide in closets and think we’re different. I don’t *allow* anyone to think I’m different.”

6.2.4 Sam Hunter

1971 wasn’t a standout year for Sam Hunter. He fell seven feet from a building and fractured T12. He went to a general hospital, spent over four months on a Stryker Frame after a T10-L2 spinal fusion, and was told by his doctor that he might be able to get around in a wheelchair if he was lucky.

In 1972, things looked up a bit. He spent a few weeks at a SCI Unit, learned to walk on braces, and got enough functional return that he’s neurologically L4, which enables him to get around well on crutches and one long leg and one short leg brace.

Sam went back to the Florida marina that he’d managed before his accident, but his former employer, himself a T5 para, told him he had no need for a handicapped individual in the business. His wife divorced him. 1972 wasn’t all that hot either.



Sam met Joan, his second wife, while visiting Colorado for a check-up. Joan was from a farming background in Nebraska, and Sam was born and raised on a farm in Michigan, so they shared some common blood and a few other things as well. They moved to Nebraska, bought a small farm, got married and started to build a life.

Sam's farming over 900 acres now—soybeans and corn, both dry land and irrigated. He puts up some hay, a little alfalfa and is starting a feeder pig operation. It hasn't been easy, but it's what he wants to do.

"You might as well do something you like. Who wants to go to a nine-to-five job in an office and let the walls close in on you all day? It's hard to explain. I like working with livestock and I like to grow crops.

"Through the tough years and the dry years before I put in the irrigation well, I took every damn dime I could scrape up from my benefits, and my wife worked and she dumped everything she had into it, and there's times when we ate, but we didn't eat so well. And now I've got it to a point where it's self-sustaining and 'I'm starting to realize some profits out of it. And I don't want it ever said or thought that the government helped me on this. Because that damn little three hundred-odd dollars a month sure as hell didn't put this place together."

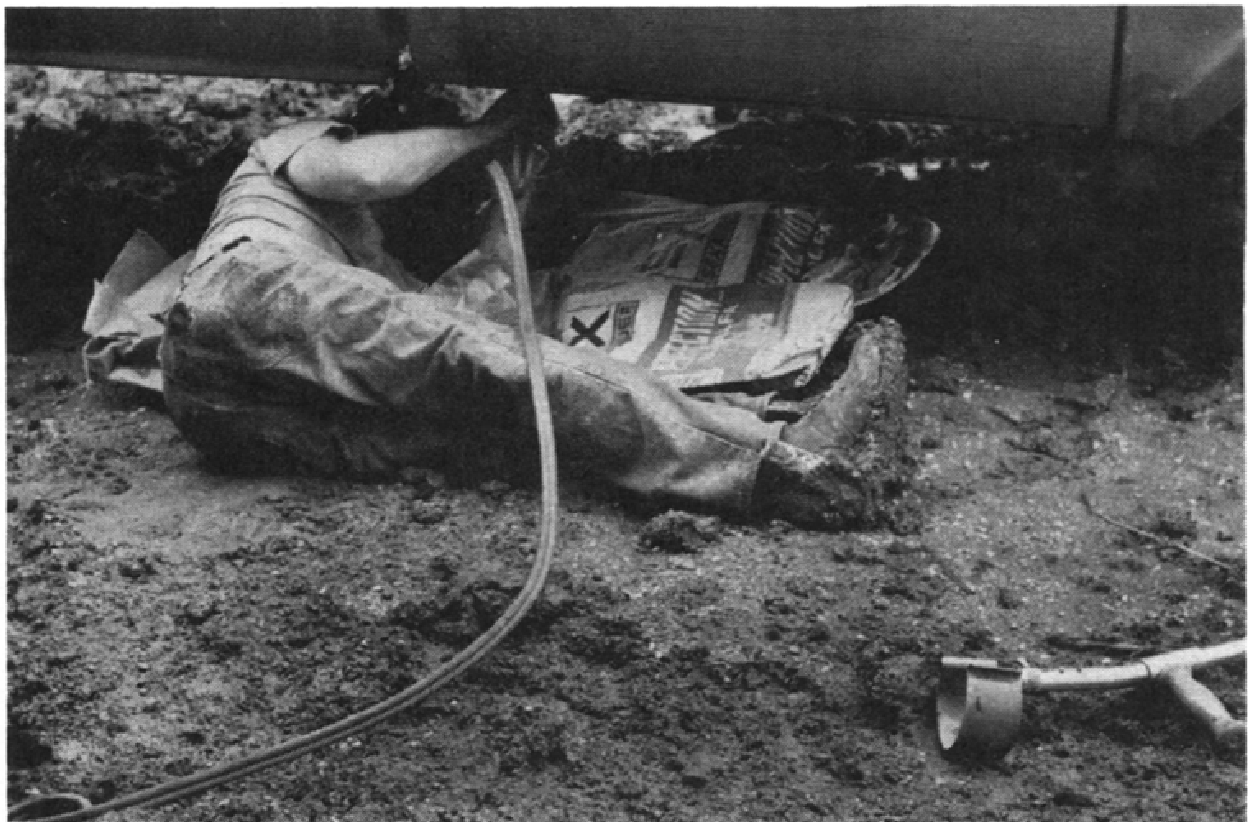
Sam Hunter has a problem. His farm, though doing well, is still marginal. Any farmer endures fickle weather and markets, unpredictable fluctuations in cash flow and very scary mortgages, and Sam still needs his benefits to keep his farm. The only way to keep them is to be listed as totally disabled.

"Either you are, or are not, handicapped. If you're considered 100% disabled, you can't earn a dime. But if you're actively engaged in employment or a business of your own, then you're not considered, as far as HEW goes, as 100% disabled. You can become gainfully employed and self-supporting without their help. Either you is or you ain't."

Sam's in between. He thinks that in two years, he could make it on his own. In the meantime, he needs his benefits.

"Just at the point where you think you're gonna get going good, and it's a little greener on the other side of the fence, and just before you can climb over that fence, someone turns on the juice and fries you good. And that's the only way I can put it."

So Sam pretends that someone else is farming his land, and hopes that things will stay level a little longer. And while he's pretending, he's a working fool.



There had been an inch of rain the night before we arrived, and nobody was turning a wheel to farm. Sam's first act of hospitality was to pull my van out of the mud. Then we had breakfast with Joan and his dad and new baby. Then he announced that since he couldn't work today, he was going to relax by cutting the back off an old pickup to make a utility trailer, and he was off swinging his way through the mud, crawling under the pickup, then over into the engine cavity with an acetylene torch. The man moves like a buzz saw. I asked him how he handled the physical demands of farming, and it was obvious that he doesn't consider it a remarkable feat:

"Everything's so mechanized nowadays. You don't lift much because you got hydraulic loaders on your tractors. Most of the equipment is hydraulically operated. Sure, there's things that's difficult. That's one reason my neighbor and I, we plant together because he's able bodied. With us two working together, it saves him dollars and it saves me having to hire help."

He handles his own harvest. "You combine it, you augur it into the truck, you back your truck up to the augur, and you augur it into the drier, and you augur it into the bin. I mean, what's the manual labor involved in that? It's all mechanized."

And that's all there is to it. Plus a lot of savvy and guts and hard work and getting to know the banker real well and maybe keeping the feds in blissful ignorance for awhile longer. But it's a little bit like being the first man on the moon and not being able to tell anyone about it. He's justly proud of his accomplishments in the face of his injury, but who can he tell?

6.2.5 Deanna Gonzalez

Deanna's a Papago Indian married to Frank Gonzalez, a Mexican-American. She has three kids, raises them without hired help and is a C6,7 quadriplegic. In fact, two of the kids, Spot and Puppet, were born after Deanna's accident. That, I thought, is remarkable.

Well it's not remarkable and it was a mistake for me to think so when visiting her.

See?

The Gonzalez' live in Ajo, Arizona, a small town in the desert southwest of Phoenix. The desert is beautiful and the town is not, being a typical Phelps-Dodge copper mining town with huge stack, designated wastelands, blowing tailings, proliferating mobile homes and, presumably, a grateful work force. Frank works for the mine, but this day he's tinkering with an old Scout which he says hasn't run in months.

The house is modest, surrounded by a fence, dozens of kids and dogs, and is an unpretentious part of a pleasant neighborhood.

Deanna invites us in, and I sense a shy, warm, personality. I prepare to tape a tale of remarkable achievement.

There's not much remarkable about her accident, which happened in a car wreck on the way to a basketball game. Rehab at Good Samaritan, her high school diploma work completed at the same time. So I got on to the good stuff.

Why did you decide to get married only a year after your accident? "We wanted to get married." Yup, it was a dumb question.

Did you have the kids intentionally? "Yes." Did you consult with a doctor first? "No."

And on the saga of childbirth: “In a way it was easier. I didn’t have to feel the contractions. But dysreflexia, it was real bad when I had Spot and Puppet, during labor.” That’s all. She did say that she spent an extra week and a half in the hospital each time.

Having run aground on heroism in the delivery room, I switched to the apparent impossibility of feeding, changing, bathing and nursing infants, let alone catching them once they can crawl. It seems that the most spectacular adaptive devices she uses are a special cutting board for food preparation and a velcro-attached wheelchair table for bathing and changing the baby. For the kids’ clothes, she just avoids anything with buttons, zippers and laces as much as possible. Her real aces in the hole are Lisa, her seven-year old daughter who gets things down from high shelves, Frank, who does most of the shopping, and her mother and sisters who like to take the kids from time to time. Otherwise, Deanna does it all: cooking, washing, kid repair and maintenance, housework and the shopping when necessary. She insists that she has no special tricks: “Everybody has their own way of doing things.”

And slowly it dawns on me what’s so remarkable about Deanna. Here’s a hint: “Things just seem like I had to do them this way. I didn’t plan it, you know. I don’t know how to explain it. If I wasn’t in a wheelchair, I’d just do things in a certain way. But I’m in a wheelchair, and I just do them. Do you understand?”

And at last I do understand. What Deanna has done would pass unnoticed if she were not in the wheelchair. If Deanna Gonzalez has a remarkable achievement in her life, it’s a matter of keeping the ordinary, well, *ordinary*. She is who she is and does what she does. She lives an ordinary normal life. What’s so remarkable about that? It is kind of nice, though.

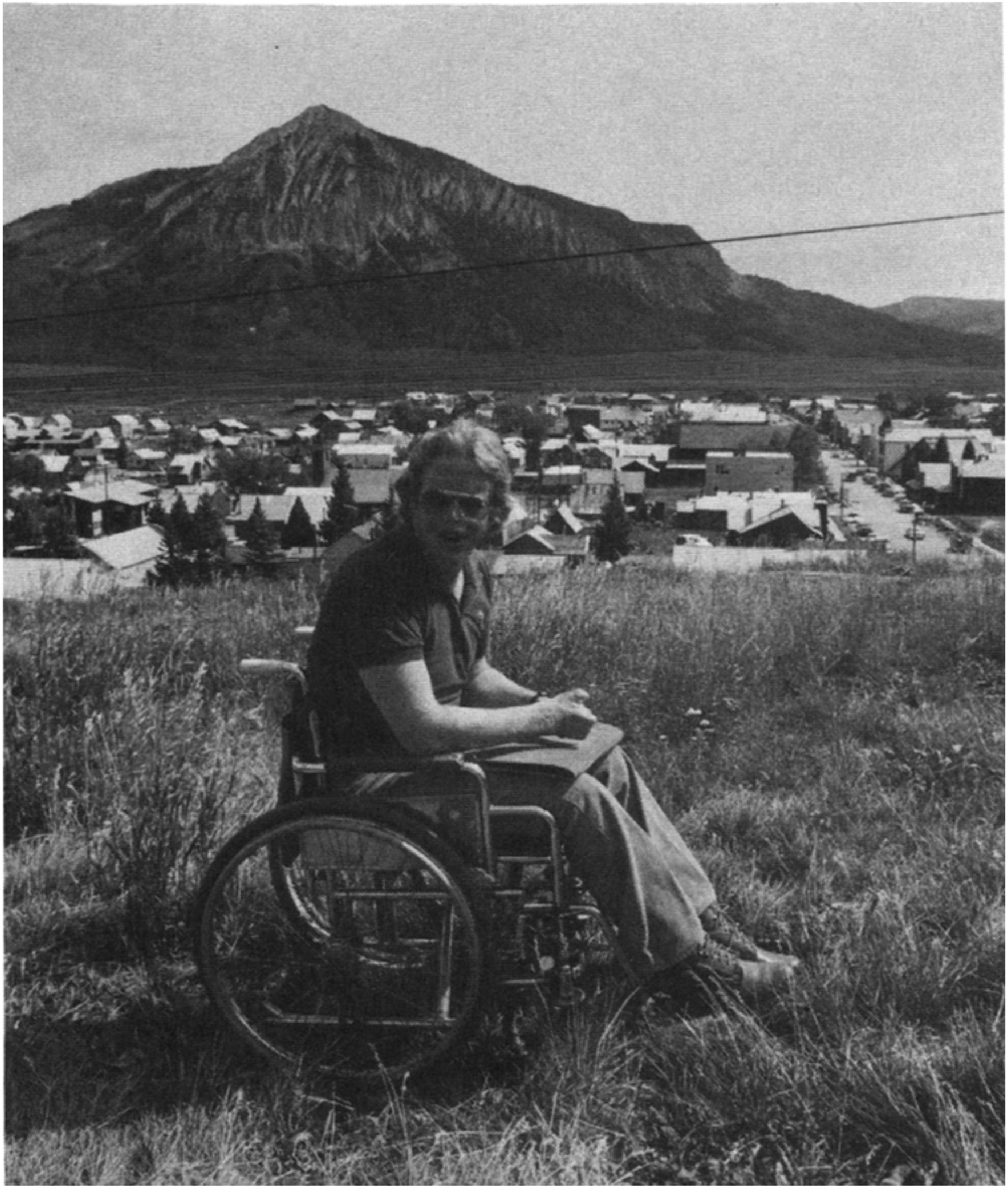
An engine roar from outside announces the resuscitation of the Scout. Deanna’s pleased, because she and Frank like to go off-roading in the desert. Frank comes in, all smiles and happiness, to wash up and crack a beer. Spot and Lisa, banned from the house while we were recording, return to tell us the good news about the Scout. They’re two of the most beautiful children I've ever seen. Puppet, who was asleep in a back room, gets an award only for his excellent manners, for we never heard from him. He may not exist.

Later, Deanna played outside with Spot and Lisa. It was a game involving a ball, a light meter, a trike, a lost shoe, a wheelchair and tenderness. There's a lot of affection at this house, and it shows on the faces of its occupants. I didn't know such a thing existed anymore, but it seems to be a nice ordinary nuclear family that works.

6.2.6 W. Mitchell

Tell me about your job.

"I'm the Mayor of Crested Butte, and I get paid $25 a month." That's almost as good as SSI. "Almost as good as SSI. It doesn't pay quite as well, but I have more fun."



Crested Butte is a boom-and-bust mining town at 9,000 feet in the Colorado Rockies, celebrating its hundredth birthday in 1980. Its population rose and fell with the prices of silver and coal, with the presence, then absence, of the railroad, with the depression and with the advent of the ski area, but now stands at about a thousand souls.

Mitchell, as he prefers to be called, admits that his office provides few perquisites and only minor powers. He's supposed to make proclamations, exercise police powers and handle complaints about noisy dogs and blowing dust. What do you expect for $25 month? But Mitchell works more than he's paid for because he's on a giant-slaying venture. He's trying to throw AMAX, a three-billion dollar mining corporation, the hell out of town. Mitchell isn't down on mining, but he doesn't like it on his own turf. Not here in Crested Butte National Historical District. No matter that mining is the reason for the historical designation. Does that give miners the right to destroy their own history? As Mayor, of course, he has no authority to fight anything. As W. Mitchell, he's well on his way to victory.

He's a complex man. Everything he says is wall-to-wall dry humor punctuated by outbursts of pure corn. Good corn. He's smoothly urbane, which paves the way for the times he wants to be vicious. For example, here's his polite version of The Controversy:

"Among the other pressures that Paradise seems to experience, we're in the heart of not only Colorado's most beautiful mountains and natural recreation areas, but also in the heart of a large mineral district. A metal called molybdenum has been found right beside our home." Since there is from four to seven billion dollars worth of this metal involved, AMAX wants it badly. Badly enough to destroy the mountain containing the ore, to build enormous tailings ponds (Mitchell calls them Slime Dumps) and to bring a work force of five to ten thousand people, plus their friends and relations and commercial camp followers, to a pretty nice mountain valley. "We're trying to encourage them to put their interests elsewhere, where they'll do less damage and more good."

At lunch, the other Mayor Mitchell appears: "Putting a mining company in charge of a natural resource is like putting Dracula in charge of the national blood bank." He gleefully shows us an article in *Iron Age Magazine* which states that the USSR is using four times as much molybdenum as it was 15 years ago, molybdenum from the USA. "So we're tearing down Colorado mountains to build Russian submarines and warheads for their nuclear rockets." Or another simile: "Restoring a mined mountain is like putting lipstick on a corpse."

Such statements have endeared Mitchell to the national press. He's been featured in the *Washington Post*, the *New York Times*, the *Rocky Mountain News*, the *Denver Post*, *Chemical Week*, *Sports Illustrated*, *USA Discovery*, *High Country News*, with more to come in *Reader's Digest* and *Harper's*. He's made network television about a dozen times, and is repeatedly described as a one-man media event. I asked if the publicity is generated by the issue or by his being the Mayor-in-a-wheelchair.

"Oh sure, the chair has a lot to do with it. It's a fantastic cause, but it's the colorful aspect of this little town with the Mayor in a wheelchair fighting the mining giant. It's really a classic David and Goliath, with the chrome as an additional factor." Chrome against molybdenum.

Mini-history: High school dropout, four years in active duty in the Marines, GED, University of Hawaii, radio announcer, political campaign worker, teacher, construction transient, political science student, cabbie, gripman on a San Francisco cable car, and sort of a thrice-born gimp.

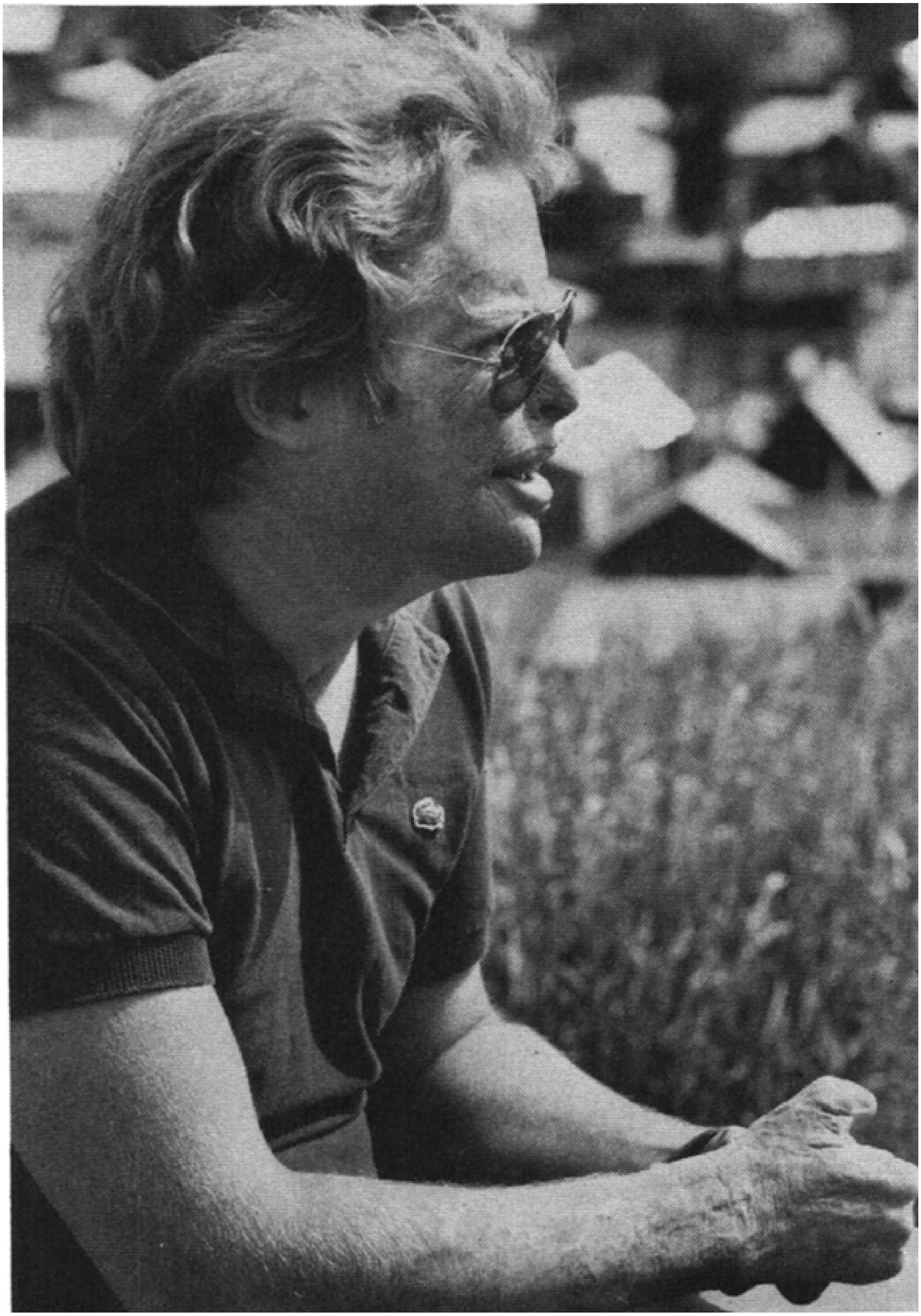
Mitchell's disabilities came on the installment plan. In 1971, a truck hit his motorcycle, the gasoline cap popped off, Mitchell ignited and a man with a fire extinguisher put him out. His fingers were burned off and other burns rearranged over half his body, including his face. He was 29.

The motorcycle accident left him with a social challenge, but didn't slow him down much. He started spending time in Colorado; first Aspen, then Crested Butte.

"Crested Butte was lovely, but it was pretty funky. It didn't have most of the amenities that I was used to in Aspen. I've later found that to be a very nice characteristic."

In 1973, with the money from a liability settlement, he bought a home and a new airplane. He holds and keeps current a commercial pilot's license, instrument and multi-engine ratings, and is a commercial glider pilot.

"This was just a beautiful, beautiful place. And with my piloting, my airplane, I was able to have a lot of mobility." It's the mobility that got him. In 1975, he had to abort a take-off from Gunnison Airport because of iced wings. He's a T12 para now, and is a changed man. "I'm being *much* more careful now —I don't ride motorcycles anymore, although I do still fly."



Mitchell went to a SCI center, and was back in Crested Butte three months later. What was his return like?

“I didn’t come out of the accident with a lot of psychological problems. Perhaps the experience of being burnt before, having that disability, conditioned me better for this. I had the luxury of growing up two doors away from a paraplegic and five doors away from a double amputee, so I’m sure that helped a lot in my understanding that you can do anything you want to. I found the wheelchair to be a restriction, but living in this small town, even with its three hundred-plus inches of snow in the winter, was pretty easy because there were a lot of friends, a lot of people to give an assist where one was needed. One of the real joys is living in a small town.”

In 1977, Mitchell was appointed to fill a vacancy on the Town Council, and first recognized the magnitude of AMAX’s plans for his town.

“I was alarmed, horrified, by what seemed to be the impact of that kind of development. I then made up my mind to run for Mayor, and it was a hotly contested battle. I formed a pretty sophisticated campaign organization, raised and spent large sums of money — $45 is the total I spent, which was probably more money than had been spent on any campaign in Crested Butte before that—and on election day, I was rewarded by a landslide victory. I won by 20 votes. It was 178 to 158. Somebody explained to me that that was 53% of the vote, which was better than Jimmy Carter had done.”

Mitchell’s up for re-election this fall, but feels fairly confident that nobody in his right mind would want to do what he’s doing for $25 a month. “To do the job I perceive needs to be done is a full-time job. It’s taken me to Washington 12 times, I’ve traveled seventy or eighty thousand miles, I’ve met people from President Carter to Jerry Brown to Teddy Kennedy to Secretary Andrus, Secretary Bergland, perhaps 20 senators, 50 congressmen and, of course, all the hierarchy of the AMAX Corporation. I’ve brought 20 to 30 million people’s attention to the issue we’re having here in Crested Butte. I’ve received and sent thousands and thousands of letters. It has been a truly amazing experience.”

That’s just dealing with the giant. In addition to the proclamations and the dog and dirt complaints, he is the Chairman of the Town Council and the liaison between the Council and the Forest Service, the BLM, the state and federal agencies which give planning grants to towns facing explosive growth, Gunnison County and the separately incorporated town of *Mount* Crested Butte, otherwise known as the ski area. “If I hadn’t got burned up, or been in a crash, I wouldn’t have enough money to be Mayor of Crested Butte.” That’s to say his settlement has been parlayed by shrewd investment — particularly in a company which he co-founded, Vermont Castings, which makes excellent wood-burning stoves —so that he can afford to spend 50 to 80 hours a week at nonremunerative work.

And the town hall? What edifice would house such a folk hero? “I have the distinction of having the least accessible town hall in America. When I became Mayor, I agreed to donate my salary back to the town so it could make the town hall wheelchair accessible. At $25 a month, I’ll have to be mayor for life!” Here it is:

"I don't spend an enormous amount of time on handicapped issues, not because I'm unsympathetic, but because I'm already working 60, 70, 80 hours a week trying to save my town from being destroyed. It seems that by being this Mayor-in-a-wheelchair, just going out and doing business as a Mayor should do it —I think people see that I'm an active person and that a wheelchair isn't a limitation to doing anything.

"The way I look at it, before I was paralyzed, there were ten thousand things I could do; ten thousand things I was capable of doing. Now there are nine thousand. I can dwell on the one thousand, or concentrate on the nine thousand I have left. And, of course the joke is that none of us in our lifetime is going to do more than two or three thousand of these things in any event."

During my brief time around Mitchell, he was constantly surrounded by women, all interesting and some adoring. I asked him about relationships. "I'm a single man. I like the company of charming ladies, but so far they've all eluded me." Do your burns and paralysis have anything to do with that? "It would be easy for me to grab that one and use it, but it doesn't stand the test. It's not valid. It's nuts to think that you have to look like Robert Redford and have a million dollars in the bank to be happy in life. There are lots of people whose compatibility goes way beyond this physical thing."

Recent foolishness and planned indulgence department: "We hear the argument constantly, when we're trying to defend the wilderness, that the handicapped and the old can't use it. Well that's not so. I just completed a raft trip down the Black Canyon of the Gunnison, a raft trip that I doubt 200 people since man came on this earth have taken. I did another raft trip down Westwater Canyon, on the Colorado." And coming up: He wants to buy a motorized sail plane which has the capability of self-launching and of landing at airports as opposed to hayfields. He figures this would be a good thing for a para. Besides, the hayfield might belong to AMAX.

Occupational advice? "Politics is one of the most interesting areas that I think that someone who's injured can get involved in. For God's sake, we need more brains and less brawn in politics these days. And if what you've arranged for yourself is mostly having to live a brain life, and less of a physical life, then maybe politics is an area where you could make a contribution."

Hot tip: "You've already demonstrated you're a survivor. You're here, as opposed to most of the people who do to themselves what you did to yourself, and that is wind up in a graveyard. So why don't you take the hint and do something with your survival skills? Go out and survive."

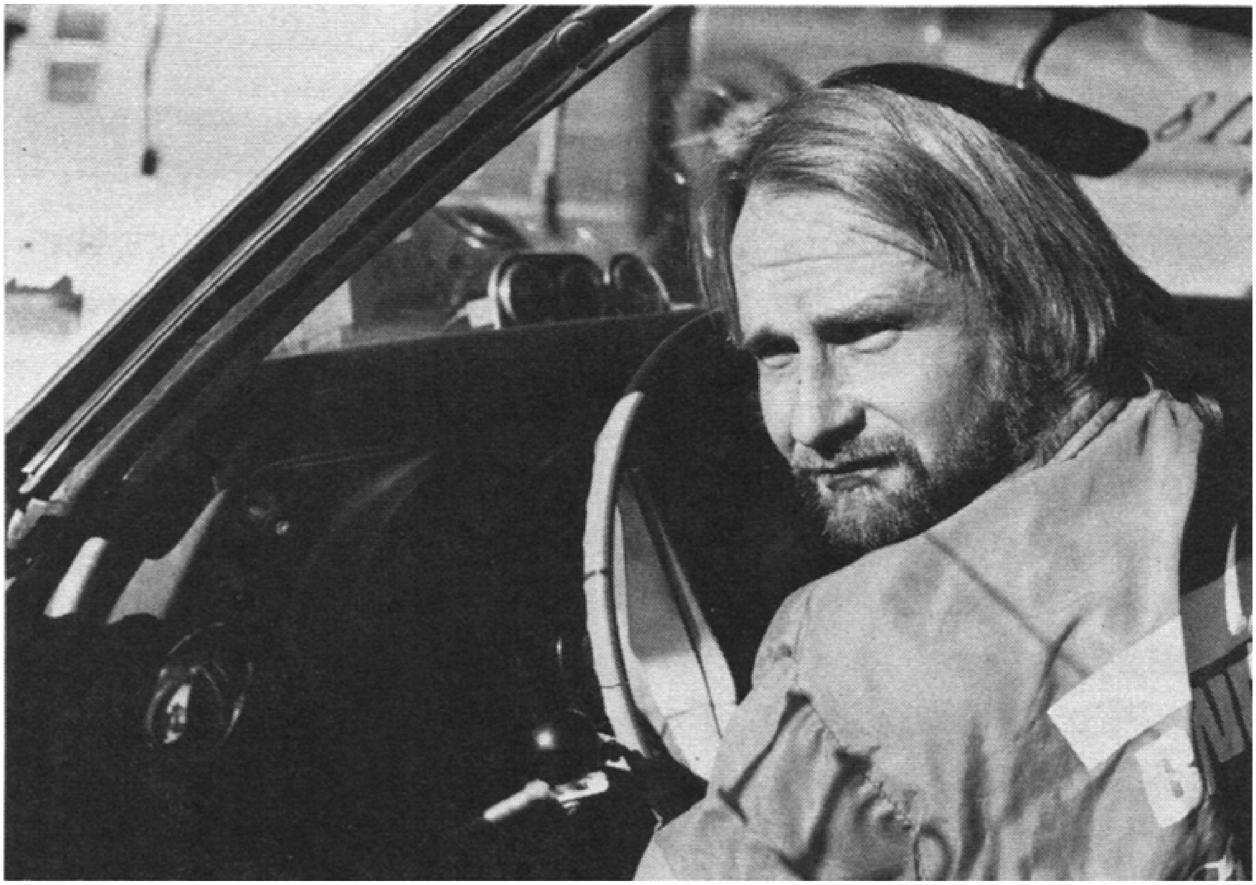
Update: Mitchell ran unopposed. A few days before the election, I asked him What if he *lost*?

"You have a lot of image problems. You've done something wrong. What if you had an election and nobody came?"

On November 6, 1979, Mitchell was re-elected mayor of Crested Butte. By a landslide.

6.2.7 Pete Brown

On August 14, 1976, Pete's '55 Chevy was turning out good times at the Bandimere Speedway. In fact, he was going 176 mph when his tie rod broke. He kept the car on the track for a few hundred yards, thought he had it saved, and that's when it started rolling. Pete jumped out and broke his back. The car rolled into a ball before it stopped.

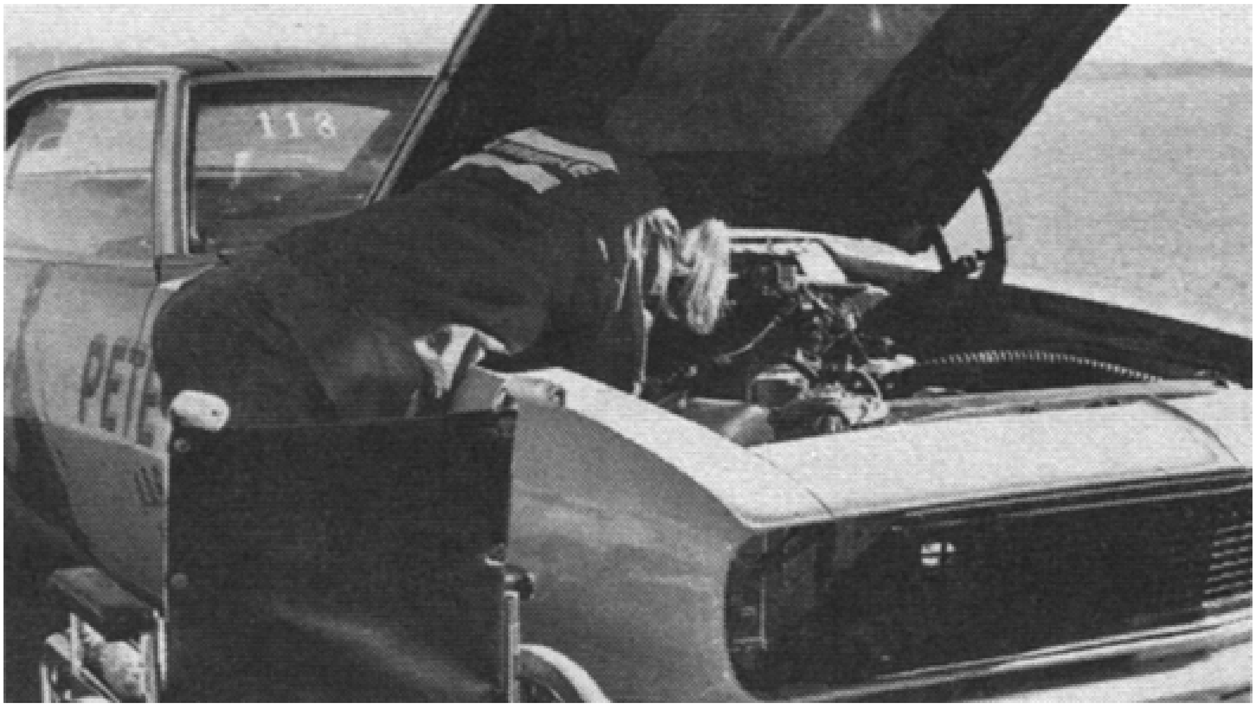


Pete's a wiry, intense person; a T12-L1 para. His speech is quiet and telegraphic, but he's friendly. He'll gladly show you pictures of what was left of his race car, and he'll take you out to the garage and proudly display his new race car, a 68 Camaro.

October 24, 1978. Pete's running time trials at the Bandimere Speedway, and isn't happy with the Camaro's performance. From his chair, he rolls up onto the fender (he doesn't need braces to do this), has the head cover off in a couple of minutes, and pulls out a broken rocker arm. He'll fix it himself—he does all the mechanical work on the car.

In the past season, Pete has raced 26 weekends, and he guesses that adds up to 200 individual races. It was a good first year for the car, and he picked up almost 1,500 competition points and a couple of sponsors. He feels that sponsors will eventually make the car self-supporting.

Is he as good a driver now as he was before his accident? “No, I’m kind of skittish of the car. I almost rolled this one about two months ago. Blew a tire.” Skittish or not, he races three out of every four weekends during the season and spends weekdays working to get the car ready for the next race. He also puts 50,000 miles a year on his van and spends time power-boating, trap-shooting, hunting and just going for trips with friends. And here’s what’s interesting: he doesn’t have a job and he’s not rich.



Often when we describe human success, we speak of employment or occupational accomplishments. It’s easy for a workaholic to assume that work defines the man and to forget that there are other significant ways to succeed in living. Or, for that matter, that man should define his own work. Indeed, there are lots of us who would define success as being able to *not* work, but somehow we think we have to work hard to secure that privilege. I think Pete’s work ethic is pretty healthy:

“I’m *able* to work. I’m not saying I’m not able to work. I’ve had a lot of people tell me that I should be getting back in school and taking up another trade, but I don’t need school to work. I know how to work on computers, I know how to work on machines, I was working at Acme Precision as assembly foreman … I’ve worked for IBM and Storage Technology. My favorite job was carpentry work, and I still do a lot of that. If someone wants something built, I can get the stuff and build it for him. I enjoy doing auto mechanic work …” But:

“It’s hard to get involved in something if you really don’t want to do it. And I really don’t want to do it. I *want* to do it, but I just don’t want to do it when I *have* to do it. You work enough to make enough money. I just live a normal life, you know. It doesn’t cost that much to live.”

Pete likes *work* alright; it’s *jobs* he doesn’t like. Amen. I like the fact that he’s not wasting much energy achieving other people’s remote objectives. He works for his own goals, and I call that a success. And if he can consume less and make do with less, I like that too.

As to the rest of his head: “I felt that I did what I did to me, so I have to live with it. You know, there’s no one else to blame. I can’t say I haven’t felt sorry for myself because I did it to myself, but as far as being emotionally upset, I haven’t been. No.”

I asked him if he was ever embarrassed by the chair. Turns out he’s embarrassed by “this raggy old chair,” but not by his new one. “I’ve been dating a lot of young girls here, and it hasn’t seemed to bother them a bit. I mean it doesn’t bother me; why should it bother them?”

Has the accident changed his life? "I *have* changed a lot. The people I'm hanging around with now are just a different type of people. Nicer people, you know. I just felt that I was going to change my life, and I did."

6.2.8 Larry Quintana

This guy is hard to figure out, as if he's a front for some benign underground organization whose identity should be obvious to me but isn't. He looks like Meher Baba and talks like a kindly Godfather, which is to say he looks wiggy and acts mellow.

He seems to run things, whatever those may be, and people around him anticipate his needs and wishes intuitively. There's a sense of mutual dedication and devotion here, perhaps a sense of service, that I've seen elsewhere only in a Buddhist community I once hung around. Larry is incredibly tight with his friends.

His speech constantly alternates from literate college English and Spanish to equally literate and infinitely more colorful street vernacular. The latter has been somewhat suppressed here as a gesture to scandalizable librarians, but we're all the poorer for the purging.

The speech shifts facilitate his role shifts —there are visible traces of radical revolutionary, love-and-light people-freak, teacher, preacher, racial synthesizer and compassionate urban guerrilla. The only adjective I feel safe with is charismatic.

He's such a complex person, at least to me, that the only way I can describe him is to tell you the obvious historical stuff, and then let his various identities inform you about what has real significance for him.

And after all is said and done, I still don't have the foggiest notion what Larry Quintana actually *does*.

Larry got it in a car wreck in 1964, when he was 17. Really got it. He's a C5-7. Reclining electric wheelchair, arm braces and all.

Eight months later he was out of the hospital, having graduated with his high school class during the same period. He was soon working as a volunteer teacher's assistant at a junior high school in his hometown, a job for which he later was paid. He knew he wanted something else, but didn't know what.

The rehabilitation hospital wanted him to go for a college education, but his working class background made him feel that a regular job was the only route to self-esteem. He finally wrote Washington, DC, for help ("To whom it may concern"), was miraculously hooked up with State Rehabilitation, and was soon a freshman at Mesa College.

New lifestyle. The artificiality of any college. Coping with his body. School was hard at first, and he stayed with it only because of a lot of help from his friends. He ran for vice president of the student body, partly to make friends and mainly because the office carried a stipend. He won. He ran for office every year thereafter through graduate school, and won every election.

After a transfer to the University of Colorado, he was able to maintain a 4.0 grade point average. He also was married and acquired a lot of fiscal responsibilities, so he started hustling every government and university program he could find. He continued winning office, which now paid $200 a month. He just couldn't understand why the campus wasn't completely accessible yet, so he set up an accessibility advocacy program for which he earned graduate school credits. He had some Social Security, and his grades got him an excellent fellowship so that he could go on to his master's degree in community planning. He received his postgraduate degree in 1974.

Three months after his graduation, he went to work for HUD as an intern planner, then as Spanish-speaking coordinator for the, region, then as a technical planner in Denver, and now takes care of HUD's 701 Program (Comprehensive Planning Assistance for the Office of Indian Programs). His job is to evaluate and process planning grant applications from the various Tribal Councils and to facilitate outreach efforts through his field representatives.

For recreation, he teaches school. For nothing. He and his friends feel that a high school education is mandatory for anyone now, so they're talking kids back into school and keeping them there by helping them in any way they can. He likes music, photography, fishing, going to the mountains, political exchanges and whatever his friends want to do. He's still married, and he and his wife have been to Mexico twice. He doesn't have a hired attendant unless travel makes it absolutely necessary.

And that's all I think I know for sure about Larry Quintana. Here's his version.

After SCI: "I know I bit shit for two years, I know I did. I mean, I hated people, man. I could not understand what in the hell was going on. Now all I can tell them is, you're gonna go through this and you're gonna do it yourself. Hell, I don't know when you're going to get over being depressed, but when you *do*, and when you feel like you're not going to be crying every damn day, do something. Get out of bed, man. Quick!

"I woke up one morning, I was in Montrose and the air was really smelling good, and I took this surge of really good air and I thought, *I'm really alive. I didn't die. And I'm gonna do something. Today.* And I think that can happen to anybody. You have to allow it to happen. And when it does happen, you'll know, and that's when it's time for you to move."

Has he changed? "I am not the same Larry Quintana. I went from Larry Quintana (Anglo inflection) to Larry Quintana (Spanish inflection). I wanted my own identity, and I was a totally different person. I know I'm not the same guy. There's no way I can be ever-ever, and I don't know if I want to be. I kind of like myself now.

"I've caught a lot of hell for my Diplomacy and Tact, as someone put it. People in wheelchairs have to be very, very to the point in order to get things done expediently. I think I have to be more aggressive than most people, because if I'm not, I can't get my physical needs taken care of. I know I cannot walk from one place to the other, and if I'm in bed, or if I'm visiting, the fastest way of getting something done is to be very much to the point of what I need and tell someone. I think there's too much hand-holding, anyway. Wasting time."

Re sex: "I think guys in wheelchairs, if they would just *learn*. Hey, I can take care of that. Quick. And feel that way toward ladies. I think if you think you're pretty, the ladies think so too. If you feel good about yourself, other people feel good about you."

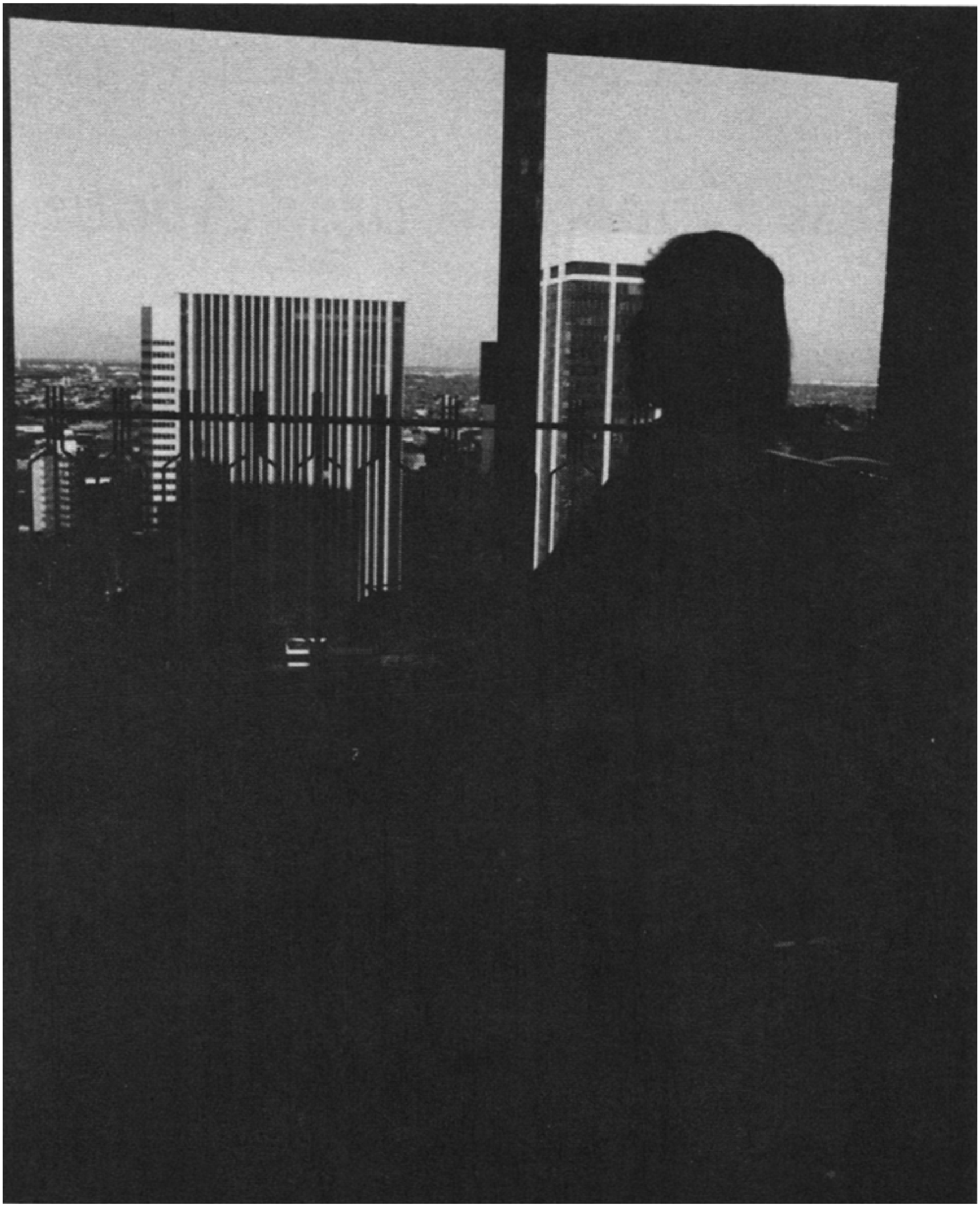
Failure? "If you don't make it, you cannot blame it on the wheelchair. Don't tell me that because you're in a wheelchair you're a tramp. Don't give me an excuse — I can't get behind the concept of failing and having a rationale for it. If you want to get behind the wheelchair for an excuse, I don't respect you. It's a copout. And it's a damn good one."

Discrimination? "I often wonder if getting into a car wreck, getting what most people consider messed up, hasn't really been an attribute. Because I sure see some sad people that have no compassion. It seems they have no compassion for each other. I am a minority, I'm a Mexican, and I can be in the wheelchair and look at racism and tell other minorities: Man, I know. I *know* what it is to be discriminated against. To the bone. I think it's terrible. Sad. Probably the most saddening thing of my life."

As Larry points out, his friends look like the United Nations on parade. He feels that for a person in a wheelchair to make an ethnically derogatory remark is about as scummy as you can get, because that's denying the facts of our own existence. I didn't want to paraphrase in this section, but that librarian is breathin' down my neck.

And about his recreation: "Almost my entire life, that is off work, is recreation. I just enjoy being alive. Actually, I'm probably just basically a happy person. I do not like depression." If you should surmise that he thinks depression is an indulgence, I'd have to agree with you.

Offered without comment: "If you can't find an attendant, you better find a lover that can take care of your ass. If your lover can't take care of you, send her back home! Don't make love to her. Tell her. I want you to expand your life, but I want my life to keep going. I love my health. I mean, if you love me, take care of me."



Here is the most animated thing Larry said. You can't see him light up with earnestness and pure benediction, but I could. You may not know that he can be cynically trite if he wants, but right now he doesn't want to. Had this little speech come from Richard Pryor or George Carlin, you'd call it the affectionate wind-up. Well, Larry has a highly developed sense of theatre, but I think he believes this:

“The best thing for anyone to do, is *SMILE, MAN!* Get behind a smile, even if you don’t mean it. Because if you smile, and ask them to do something, they will enjoy doing it. People do not do anything they do not want to do. So don’t forget that man opening the door for you, or you (me), bringing that coffee up; you did it because you wanted to. People don’t do things they don’t want to do. So smile at ’em. IHELL, MAN*, I think the smile is the biggest thing you can give to anybody! Express a lot of love to people.”

And maybe, after all, Larry Quintana is not complex. Maybe I’m unable to recognize simple concern for all people expressed so directly, because that happens so seldom. This guy’s hard to figure out.

6.3 Op Ed I

6.3.1 A Few Cheery Words About Despair and Anxiety

Feeling, ah, subdued today? Been through the rendering plant, strained through a sheet by the freaky flukes of fate? Well, now. . .

Despair is a perfectly reasonable response to your accident. Spinal cord injury is one of the crowning jewels of colossal bummers, psychologically and physically, and there is every reason for displeasure. Nor is it unreasonable if your body and mind deny the gravity or permanence of your injury. Why accept the unacceptable?

(There is even a cherished myth around the halls of rehabilitation that denial and mourning periods must precede successful adjustment. Statistical evidence refuses to support the idea, but glom onto it if it feels right to you.)

Despair is a word I use to describe an immediate emotional reaction. It is normally related to anger, and anger is an implacable force. Anger/despair is acute —it is so powerful that it overwhelms reason and intention. It’s strong stuff. It draws off so much energy that the mind and body reach a point where they can’t sustain the energy demand. Some breaker inside clicks, and it’s over. Not swept under the rug, but gone like a bad dream. The good news about despair is that, like an old shoe, it wears out. It burns itself out without damaging the host organism, which is you.

Since despair is a paper tiger, lacking the basic stamina to persist, you have the choice of waiting until it disappears or forging ahead with the sure knowledge that it *will* disappear.

The greater and more enduring problem, the one this book addresses, is anxiety about your future. Will I like my life? Can I live and love and laugh again? Can I get around, get aroused, get off, get a job, get satisfaction?

Apparently so. There’s evidence around (Trieschmann, pp. 49, 63) that, on average, SCI’s are no more depressed than AB’s. And that quads are no more depressed than paras. I think that’s interesting. More severe disabilities aren’t statistically connected with greater depression, lowered expectations, or decreased satisfaction with life. Hmm. Certainly the people in this book are not best characterized by their bitter dissatisfaction with life. All this leads me to the following speculation, entirely uncontaminated and unsubstantiated by scientific opinion, about happiness and unhappiness.

During the Crimean War, medical field camps divided new patients into three groups. The first group was those sure to die in spite of treatment, the second group was those who could and should be treated successfully and the third group was those so slightly injured that treatment was unnecessary. The middle group, of course, got all the medical attention. This division was called *Triage* and was performed by a Triage Officer.

The human mind has a Triage Officer of sorts. He assigns emotional and physical events to categories: good or bad, pleasant or painful, happy or unhappy. A large portion of our experience falls between the two extremes, and is automatically processed without much effort or recognition. The extremes, therefore, become the Officer’s preoccupation, so we might as well forget the middle category and call this mind process Duage. Hence, Duage Officer.

Now the mind’s Duage Officer is being asked to sort out happy from unhappy just as he did before the holocaust, the war, the accident. He’s supposed to report to the brain in no-nonsense computer talk. Yes/no, on/off, happy/unhappy. But he’s got a problem. The situation is changing fast and there no longer seem to be absolute guidelines for his assigned task.

It's easy to see that there *are* no objective criteria for describing events and emotions as happy or unhappy. If you're hungry, bread and water taste fine. If you're broke, $5 is a lease on life. Men have written that they have only lived fully during times of horrifying war or oppression. Prisoners have found blessed miracles in dungeons. Childbirth is painful and rewarding. Moments of past danger become treasured anecdotes, and stress creates finest hours by the eon. If you're healthy, a common cold is a catastrophe. If you're paralyzed, a transfer is a triumph…

You can only go for so many days saying "It's good today" or "It's bad today" before you learn that your mind is incapable of consistently calling things good or bad.

Consider: Pleasure is what we like in life, and pain is what we dislike. Neither one is what we consistently get. Our circumstances vary dramatically. The only way the mind can cope with these fluctuations is to have a floating reference level. Homeostasis. There is no absolute definition of pleasure and pain. The definition is itself variable, and moves relative to other factors. That's because the Duage Officer, who is a bureaucrat at heart, describes equal amounts of our experience as good, pleasant or happy, and as bad, painful or unhappy. He's sort of simple-minded, and all he knows is that it's his job to maintain equilibrium by shifting the pleasure/pain median to suit the altered circumstances. He wears blinders, like most bureaucrats, so he succeeds admirably.

Now the Duage Officer is a cute little guy, but he's a little hard to take seriously. What can be taken seriously is the fact that we do, normally, spend equal amounts of energy on being happy and unhappy.

We all know high rollers who exult gloriously, and big losers who sulk miserably. They are the same person. We know middle-of-the-roaders who have very laid back responses to the vagaries of life. They seem incapable of great joy or great sorrow. The amplitude of the ups and downs will vary from person to person, time to time and circumstance to circumstance. But we all establish a threshold with pleasure and pain equally disposed on either side. Pleasure/pain homeostasis.

Your accident may have knocked your Duage Officer on his keester for awhile — bureaucrats aren't noted for their great flexibility, only for being consistent — but he'll re-establish himself in your new internal government because he's needed and he's good at his job. Besides, by now you know that happiness and unhappiness are two ends of the same stick. If you have one end, then you have access to the other.

Your circumstances have been rearranged and your pleasure/pain median will follow suit. This is not a defeatist lowering of expectations, but a mature adjustment to change. The point is that there is every reason to expect a complete return to the same appreciation of life that you once had.

Wasn't it Edith Wharton who said that if only we stopped trying to be happy, we could have a pretty good time? She was no gimp.

> "SCI alters life radically, but in some important ways life is not really changed. You're going to face problems that may seem a lot tougher, but maybe aren't a lot tougher, than everyone else has to face."
>
> —Don Scanlon

> "It really changes your perspective. The one thing I really come back to is that I've gained an incredible sense of perspective. Different people's realities; how relative the whole bit is. For that, I'm grateful."
>
> —John Galland

> "You can look for the good and find it, or look for the bad and find it. I choose to look for the good because it's much less depressing."
>
> —W. Mitchell

6.3.2 Higher Lesions and Higher Learning

Now that your spinal cord has been tampered with, you may have decided against becoming a professional ball player, telephone lineman or stevedore. You have probably been told that the key to expanding your occupational options is MORE EDUCATION. The trouble is that if you're paralyzed, if you never intended to go on to higher education, if you're older than the student body at large, if you're not much into books, if you don't know which schools are accessible and have special services for disabled students, if you're broke, if taking your brand new wheelchair into a college environment is scary, or all the above, then going to college can look like an endless fishladder of insurmountable hurdles.

Not so. One man, Professor Timothy J. Nugent, changed all that back in 1947. He had the then unfashionable notion that the severely disabled have the same aspirations, interests, talents and skills as anyone else and therefore have the right to higher education. Tim Nugent was a good fighter and a good con artist, then as now, and was instrumental in creating the Division of Rehabilitation-Education Services at the University of Illinois at Champaign. Since 1951, the University has averaged over 225 severely disabled full-time residential students each year, many of whom are represented in this book. Nugent's ideas and programs have become widely accepted and schools which meet the needs of the disabled are now to be found just about everywhere.

Look in the bibliography to find access to information about schools which make an effort to help disabled students, then briefly transport your mind to one of these schools, the University of Arizona at Tucson.

Lots of people know that Tucson is a pretty pleasant place to visit. Not too many know that its University is a paradise for disabled students.

It's partly the level ground, partly the easy climate, partly the accessible buildings, partly the sheer numbers of disabled students (300 disabled, 125 in chairs) and partly the wholesome attitude of both able bodied and disabled students who are constantly exposed to each other; these things all appeal about the place. But mainly, it's the efforts of the Office for Special Services for Disabled Students, which will do the following things and more for disabled students who ask:

- Provide all necessary help for entrance examinations, admission and registration
- Direct students to sources of financial aid
- Recruit readers, writers, interpreters and wheelchair pushers
- Recruit and train attendants
- Assist in finding suitable housing
- Repair wheelchairs and other devices through their Mobility Repair Service
- Provide career, personal, group and academic counseling
- Act as student's advocate with the State Department of Rehabilitation

The results of the program are amazing. There are so many wheelchairs circulating on campus that they are part of the scenery. And every chair that blends into the student body creates dozens of able bodied students who see people instead of chairs. This place is a sure cure for a gimp's feeling out of place and a sure cure for a normie feeling awkward around a wheelchair. And seeing this school, or any of many like it, would be a sure cure for any fears you may have about going to college. And all of this is why this preamble precedes the following section introduced by Gene Tchida, one of the main architects of the University of Arizona program.

6.4 Lives II

6.4.1 Gene Tchida

The Special Services for Disabled Students program at the University of Arizona (see preceding section for description) is coordinated by Gene Tchida, a C4,5 quadriplegic with the best possible reason for being helpful. He came so close to spending his life in a nursing home, was so victimized by primitive care, was so uninformed of his real abilities and expectations and was so deprived of opportunity that he desperately wants to be sure that these things never happen again. Ever. To anyone.

Gene was in an auto accident in 1956, when he was 16. Here's his "rehabilitation" history, which should be read with the understanding that his accident predates the advent of rehabilitation as it is known today.

General hospitalization in Globe, Arizona. Tongs and traction immediately applied. Moved to Good Samaritan Hospital in Phoenix, which then offered only general hospital care but at least had a Stryker Frame. (Good Sam's SCI Center, established later, is now a symbol for enlightened rehabilitation.) Transferred to a Crippled Children's Hospital which was custodial, not remedial. "It had the look of an old people's home with young people in it. There I was, 16 years old and looking at something pretty bleak." Indeed, it was very bleak. He couldn't feed himself. He'd never heard of hand splints. He was pushed wherever he went, because electric wheelchairs weren't part of what the hospital offered. There *was* one therapist who knew enough about the fledgling subject of rehabilitation to get him released to family care at home after six months.

His family was supportive, took care of his attendant needs and encouraged him to finish high school on a home-bound program, which he did. That completed the goals he had set for himself before the accident. He'd toyed with the idea of joining the Navy, had never considered college, nobody in his family had ever gone on to higher education, and he had no idea what to do next.

Friends and parents suggested trying college. He made an appointment to see the assistant dean of a nearby junior college, but the dean's office was completely inaccessible. "That was a frightening experience. How was I going to school when I couldn't even get in the door?" That experience spun him into seven years of "semi-vegetation," as Gene puts it. A lot of reading, a lot of television and a lot of frustration. A lot of killing time.

Gene's older sister, always concerned, started asking around the State Department of Vocational Rehabilitation. After a psychological assessment, he qualified for three months of intensive occupational and physical therapy at Rancho los Amigos Hospital in Downey, California. Gene credits his sister and Rancho with turning his life around.

Rancho: After eight years, Gene was, for the first time, exposed to real rehabilitation. After eight years, he was, for the first time, outfitted with hand splints and an electric wheelchair. After eight years, he could go somewhere without asking.

"I saw rehabilitation, and I saw many young people my age, some younger, some older, who had similar situations. It opened all kinds of doors. I could see that there were areas that I could move out into. There was a sense of identity, a sense of importance, and the relationships that developed started to show that I was normal on the inside whereas there was some physical loss on the outside. That was really eye-opening for me."

The rest of it went quickly. He enrolled at Arizona State University at Tempe that summer as a 25 year old freshman, and graduated in psychology. Got his master's at the University of Arizona in Rehabilitation Counseling. Worked into the Special Services program during its infancy. In 1972, he married Linda: "I've been married now six years. Ten or twelve years ago, marriage was, to me, a completely foreign idea. I quite candidly did not think that a person who was a quadriplegic got married. I think it demonstrates as much as anything my lack of understanding of what was achievable, given a person's will and desire and motivation and willingness to take chances. Today, I think it's a very natural state of affairs for me."

How would he compare his own satisfaction now with, say, his satisfaction in 1959?

"Night and day. Literally. Then, I couldn't see anything. I couldn't see the next day, the day after that. I had no feeling for future, for goals. Now, I feel that I'm really limited only in the sense that I limit myself."

How does he feel about severely disabled people adding the difficulties of schooling to the existing difficulties of disability?

“I don’t look for guarantees. I look for chances. And I think that’s what I would like to ensure —that individuals get a chance. It may be a chance to fail, but at least it’s a chance.”

So Gene seems to have experienced the ultimate satisfaction — having narrowly escaped life imprisonment in semi-vegetation, he has forged a life which gives him and others the opportunity he was almost denied.

As we leave his office together, he talks enthusiastically of the new house he and Linda are building. As we pass the receptionist, she asks him a question in sign language. He answers, apparently using substitute signs to offset his lack of manual dexterity. For me, this is humbling and heartwarming. If Gene Tchida, who definitely does not have the good hands, has time to tackle sign language because some of the students his office serves are hearing-impaired, then the rest of us can surely summon the wherewithal to rejoin this world of magnified opportunity with joy and abundant energy, simply because people like Gene have *made* it possible. For anyone.

6.4.2 Larry Bryant

Larry Bryant works in the belly of a bureaucracy and is proud of it. He wears the uniform —three piece suit, polka dot tie, patent leather shoes and a gold watch chain. There are a couple of apparent anomalies: quiet articulation, decisiveness, directness and sensitivity are not qualities that I always expect to find in bureaucrats; and then there’s the gold earring…

Larry's been through a lot of changes. He comes from an educated, fairly affluent family in Atlanta. There are many executives in the family, several holding PhD's, and he was expected to fall into the same mold. Predictably, he rebelled. He learned how to make a zip gun at the age of 12, spent a lot of time on the streets in and out of trouble, participated in civil rights efforts and generally avoided anything that smacked of the establishment.

In 1961, he moved to Los Angeles to see if he could mellow out a little. He was diving into the ocean from a 20-foot cliff with some friends, misjudged a wave and began a new life as a C4-6 quadriplegic. He was 16.

Since that time, Larry did his rehab, finished high school, got two undergraduate degrees, earned a master's in rehabilitation counseling, counseled emotionally retarded adults, participated in Project Hope, which was an effort to keep delinquent kids out of jail, moved to the Los Angeles Mayor's office, which was beginning to bring the handicapped into civil service jobs and now is a deputy compliance officer with Affirmative Action for Los Angeles County. It's a responsible job with expanding opportunities, and he likes it.

I wanted to know about some of the missing details, such as his rehab at Rancho los Amigos.

"Man, I spent *two years* at Rancho. I really didn't want to leave, you know. I became so dependent on people doing things for me that it was difficult to leave, to get back out there. Two years of that just about did me in."

He did succeed in finishing his last two years of high school while at Rancho, but feels they should have kicked him out earlier, an opinion no doubt shared by Rancho. They, like Larry, have changed since 1961. Here's some hindsight:

"Things are going to be only as bad as you make them. You can sit in that hospital room and vegetate the rest of your life. You can deal with nurses, with doctors, with other patients who are just there to create their own little world —but whatever you accept is because *you* make the choice to accept it. Therefore, if you want something good to happen, you can make it happen. The things that I wanted and the things that have happened to me are basically because I made them happen, not because I was any Superman. I believed they could happen."

But what if I'm not really bright, I never wanted to finish high school, I've got no career objectives and now I'm a quad?

"Hey, I didn't believe I was bright. I didn't believe that the State Department of Rehab would send me out of state to go to school, I didn't believe that there was a welfare system that would support me. There were a lot of things I didn't know, but I started to ask questions and, in some cases, to make people come up with an answer for me. You know, you can search and search and search sometimes, and look in the wrong place. But you've gotta make things happen for you, you've gotta believe that there are things out there for you."

This conviction didn't arrive in one flash of insight. He started with correspondence school: "I did about a year and a half, then realized that I didn't have to sit in a back room and type this correspondence work. I could actually go to a campus and mingle with the other kids. And I did and it was great."

Larry picked up an AA in business, a BA in experimental psychology, then traveled to the University of Arizona in Tucson for his master's in Rehabilitation Counseling. How was it?

"Fan-tastic. That year that I went away to Arizona was probably the best year that I've ever had. It allowed me to not just be on my own again, but to think freely. That was the best time I ever had, aside from what I'm doing now with the young lady I'm with."

Larry is quick to credit *Gene Tchida* and his department for much of the good times. "They helped me get an attendant before I got there, find an apartment; they were really nice people. There were 360 handicapped students on campus and they had everything for us. As much recreation as any other student took part in. You did everything anybody else did. You were slowed down but you weren't really limited."

He didn't date much at U of A, not because he didn't want to, but because he did a two year master's program in one year. That was a pretty demanding goal, and he's very proud of its accomplishment. But no time for dates.

That, too, has changed. He's getting married very soon, loves to talk about Esther, his fiancee, about what they do now and what they'll do later. And about how it used to be:

"I used to sit back in the hospital room and dream about going on dates, taking a young lady out somewhere, and it never seemed to be a realistic thing to happen to me. I used to think that I would never be able to have any kind of relationship with anyone. But it has happened. As I became more confident in myself, understanding what goes on around me as well as in a relationship, it just seems that it was a natural thing that I would someday find somebody who was like me, who liked the same things I liked, who accepted me as an individual and only looked at me secondarily as an individual who is disabled. And it can be the same way for anybody."

There's a stiff entrance exam getting into Larry's office. It's in the Los Angeles County Administration Building, a structure which makes the Pentagon look as complex as a gazebo. After the guard station, there's an underground maze of parking levels and ramps designed by a storm sewer engineer, and elevators which can take you where you want to go only if you take the correct elevators in the correct sequence. The office is on the seventh floor, looks out over the city, and rattles constantly from the throbbing of the helicopters that hover about like mosquitoes. Or maybe the earthquake is finally upon us. I feel paranoid in these places.

Larry, on the other hand, looks very much at home. He *is* a little surprised to be here: "It was just not in my program to be sitting here with a three piece suit — with an earring in my ear, sure —but being here and dealing with other three piece suit types.

"I came on as the County's expert for the handicapped. This was right after the Rehab Act was enacted. Basically my function is to oversee grievance procedures for individuals and to protect and safeguard the rights of the handicapped for the County. That includes advising the Board of Supervisors, advising the Affirmative Action Officer and the Board on handicapped legislation, on rights, accessibility, regional accommodation, that sort of thing. Sometimes I feel like the expert. Sometimes (groans) I don't know."

He feels that his office does a good job, but is hindered by limited budget and staff. "We get things done, but not in the volume and quality, sometimes, that we'd like to get them done." It's easy to see why: 21 employees are providing services to 65,000 handicapped people in the County.

Are there handicapped people out there who don't know how to find help?

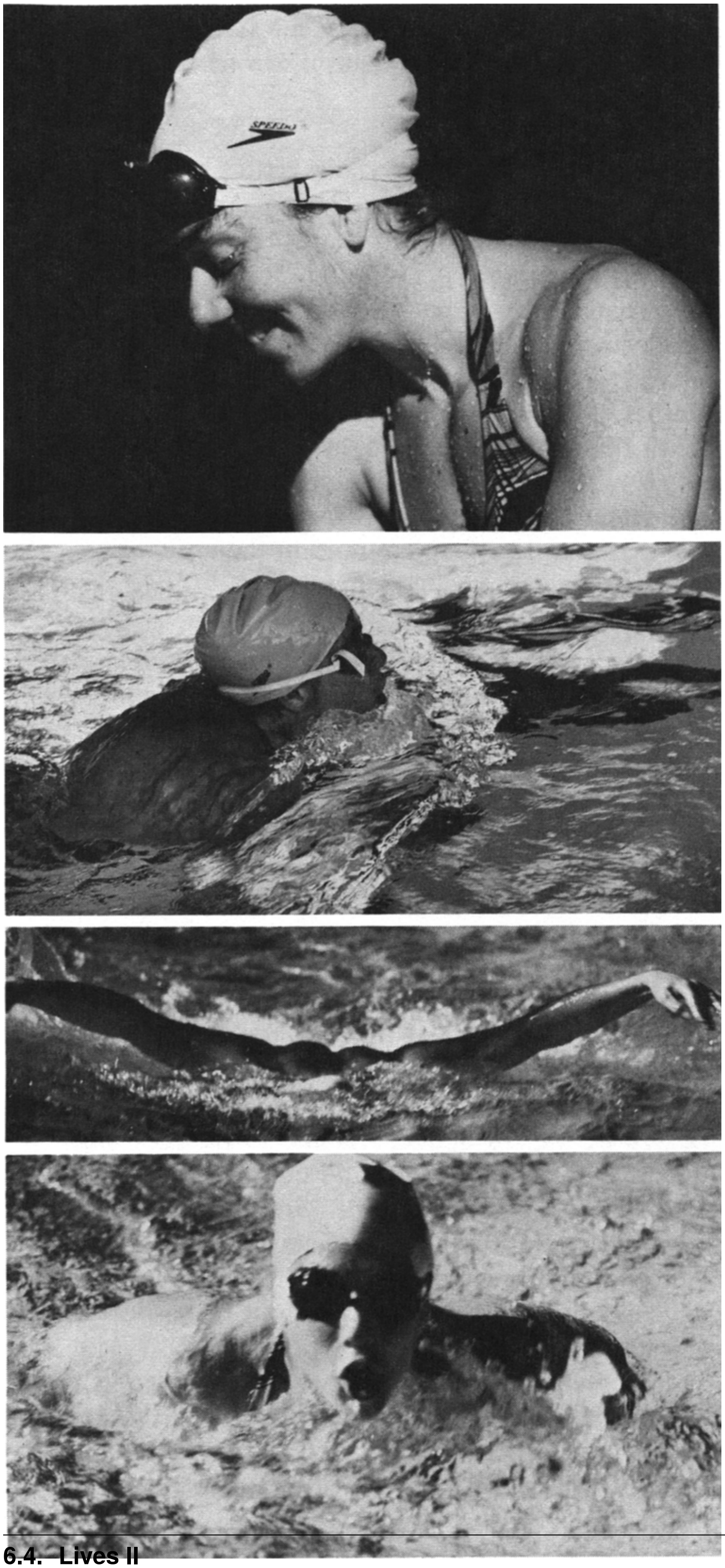
"I'm really surprised, but there are people out there who not only don't know we're here, but that there's a new law that protects them. I'm really surprised about the people who don't know about the Rehab Act, just have no idea.

"There are youngsters who are in hospitals now who don't realize that there are many things out there for them. Not just accessible curbs or jobs, but attitudes of people are now changing. So the disabled person is now beginning to realize that he can function on any level, on the same kinds of levels that everyone else functions on.

"When I was in the hospital, nobody told me that I was able to go to school, that I was able to get out in life and deal with individuals, that I was able to travel. I had no one come to me and say Larry, you can lead as normal a life, whatever that means, as anyone else can. All you've gotta do is just go for it."

Larry's been asked to do some public service television announcements aimed at getting disabled kids into Scouting. They want him to wear a Boy Scout uniform on camera. Would that embarrass him? "Are you kidding? No, I love it. Getting handicapped kids into Scouting? I *love* it."

6.4.3 Syd Jacobs



In 1974, a doctor friend asked me to drop in on a new patient of his who had broken her back in a mountaineering accident in the Cascade Range of Washington state. She had taken a fast slide down a snow slope and hit a rock. Her name was Syd Jacobs, she was 20 years old, she had a T6,7 break, looked kind of peaked and was pretty bummed out by the accident because she felt she'd done everything right and had her head in the right place just before the quick stop. What struck me was that her annoyance was over her performance, not her luck. The other thing that struck me as unusual was that, a few days after her accident, she was making plans about where and how she wanted to live and about what she wanted to do in life.

I next saw her in 1976, in Colorado, and it was clear that she had accomplished a lot of goals in a hurry. She had also become the first wheelchair jock I was to meet — light chair, no arm rests, one foot nonchalantly hooked over the web strap between her footrest supports and oozing vitality. She gave me my first inkling that I wasn't cutting the raciest possible image in my chair.

Our next encounter was in Seattle, in 1978, and her world had expanded once again. She had just landed a job in a field she felt was perfect for her and which still gave her time off to train for her other life, about which more later. She still looked speedy and her health lit up her surroundings.

And now, in Boulder for a visit in 1979, she has some things to say.

First, you should know that Syd was a competitive swimmer before her accident, which may or may not explain her dreams. They started in the hospital before she was even up in a chair.

"I had a lot of dreams about swimming. I would get in the water at one end of the pool and I'd be crippled, and I'd swim to the other end and I'd be able to get out and walk. As soon as I got up I started swimming, and I really liked it. I preferred swimming to lifting weights and pushing my chair around."

"I got involved in wheelchair sports right away, and that really was a big influence because I met a lot of people that had been in wheelchairs for a long time and they helped me make a big adjustment — just watching people that were physically fit and could get around. That really helped."

"I've been all over the country: Arizona, Virginia, New York, Kentucky, Colorado, everywhere; and in the world I've been to Brazil, England, Canada and Mexico; all competing for wheelchair sports. (She's hoping to compete in swimming, perhaps in basketball, in the Netherlands in 1980.) That takes care of the competitive side of my life. I also like scuba diving and snorkeling, kayaking, sledding, skiing on a pulk, camping …" Syd gets around.

It didn't all happen at once. Syd lived with her parents in Colorado for a few months, which was hard for her just because she had already been out and on her own. But: "Even before I got out of the hospital, my whole objective was to go back to Washington state, so the first opportunity I had I went up to see my friends for a week, and that's when I decided I was definitely going back. So six months later, I moved back to Washington."

The first thing Syd did back in Seattle was to finish off her BA in Communications, competing in wheelchair sports at the same time. Her vocational interests were a mixed bag: media communications on the one hand and environmental education on the other. Her new job may be a chance to do both.

She works for the National Park Service's Visitor Information Service, which acts as a regional clearing house for outdoor recreation information. Next summer holds the promise of working at Rainier National Park as an interpretation trainee, an opportunity Syd values because it gets her back in the mountains and because she feels the job may eventually lead to producing brochures and films.

The most remarkable thing about her job is that a large government agency was flexible enough to give her time off for training and competition. "That was one of the stipulations when I took the job, that I was going to get time off when I wanted it. At least for the first year that I worked there. But they were *looking* for a disabled person in that job."

How did she find the job? Through Handicapped Referral, an agency funded by CETA (Comprehensive Employment Training Act).

Syd dates actively and feels she's too restless to settle down. Her most recent relationship ended when the man "decided I was too self-confident for him. He was afraid I was going to dominate his life, I guess. No one's ever told me that before. (Laughs) I don't think being a gimp had anything to do with it."

About her chair: “The only time I really feel embarrassed about being in a wheelchair is when I act like a klutz. I think it’s a matter of self-confidence. If I feel confident and I can get around like anyone else, it doesn’t bother me a bit. Say, if I try to jump a curb and I miss, and all these people come rushing to the aid of the poor cripple on the street —that’s when I get embarrassed.

“If people are going to have a good perception of people in wheelchairs and disabled people in general, it’s up to us to make that perception good. And that’s by being pleasant and teaching people what we can and can’t do, instead of acting like we have a chip on our shoulder. If someone opens a door for me, fine. I’ll say thank you. But I’ll still open doors for other people too.

“I try to understand when people are trying to be helpful. If I’m pushing up a hill, got a rhythm going, I find it really aggravating when someone comes up behind me and just starts pushing me. It would be really easy to snap at them. I don’t need your help! But I think it’s really important to try to understand them. I think most people are pretty well-meaning, but you just have to be gentle with them —let ’em *know*.”

Syd lets ‘em know; she was with a basketball team on a plane to Edmonton when a steward referred to the team as wheelchair *patients*. Her response was outraged but still educational: “*We’re not patients. We’re wheelchair athletes, do you mind?*” She chuckles, and says she’s very seldom that nasty.

News flash: Syd didn’t get her summer job as a trainee at Rainier. She got something better, working as a naturalist at Hurricane Ridge in Olympic National Park and also as a researcher preparing a report on the accessibility of the park. Her daily duties include leading three 45-minute nature walks over decidedly hilly terrain, jaunts which have doubtless caused more than a few tourists to reassess their own physical prowess.

6.4.4 Lou Carello

Lou lives on a quiet street in Fountain Valley, California. The house is neat, pleasant, unpretentious. He wants to know what we're up to before he'll talk, but he's friendly. After he decides we're OK, he's very friendly.

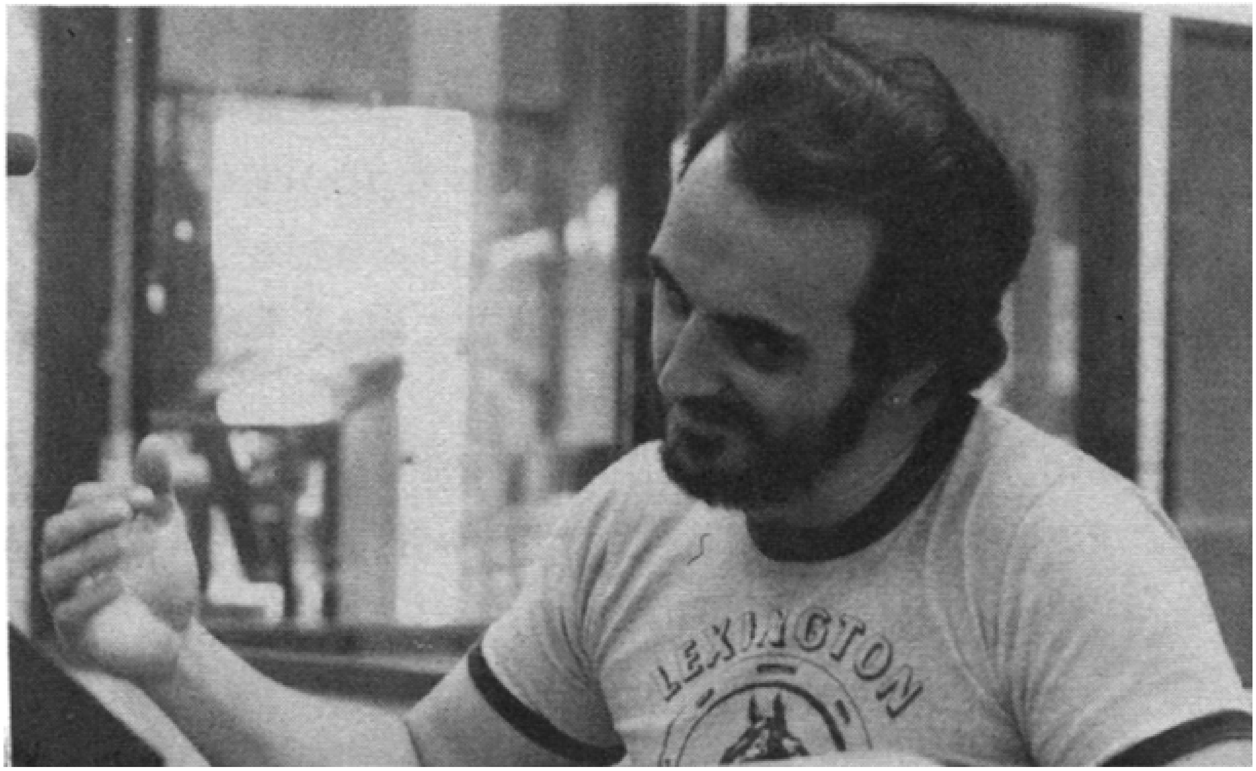
Lou's cultural background is Italian. He's proud of it and it shows in his voice and mannerisms. He has intense eyes, a boxer's quick moves and animated, mobile features. An actor's face.

He is an actor. "I was in *The Roy Campanella Story* about two or three years ago, I had a very large part in *Coming Home, Heroes*, I did a *Barnaby Jones*, I've done a *Paper Chase*, I was in a TV movie called *Some Kind of Miracle* and I was part of a handicapped movie called *A Different Approach*. There's a possibility of a movie in Boulder, Colorado, a very good part in that one, and the possibility of a TV series which would be based a lot on my life."

And before that? "I didn't graduate from high school. Got thrown out of school a couple of times, went to a reform school. I went through a system where they were more interested in disciplining me than teaching me."

The Marine Corps got Lou off the streets and provided him with some of his first positive and reinforcing experiences. They also sent him to Vietnam, where he was shot. He's a T9, with a lot of useful return. As a guess, he's functionally about L4.

We continue our conversation at the local Nautilus Gym where Lou works out regularly. He likes what it does to his body and mind. He'd do a set of exercises, then talk. If he sounds breathless at times, he is.



What about after his rehabilitation? "I'm a former junkie. I wanted to work with narcotics addicts, but society says if you don't have a piece of paper, you're not qualified. And unfortunately, they wouldn't take my real life experience."

Then he got married. "I had the very fortunate thing of finding a woman I really loved about three and a half years ago. It's kind of turned my life around. Things are going right for me, you know?"

How did the acting career happen? "I was at the VA Hospital one day, pushing down the hallway, and some guy says How'd you like to be in a movie? Why not? So I went down to his room and this guy gave me a piece of paper, I read a few words and they put it on tape, and about three months later I got a card in the mail telling me to go to Howard

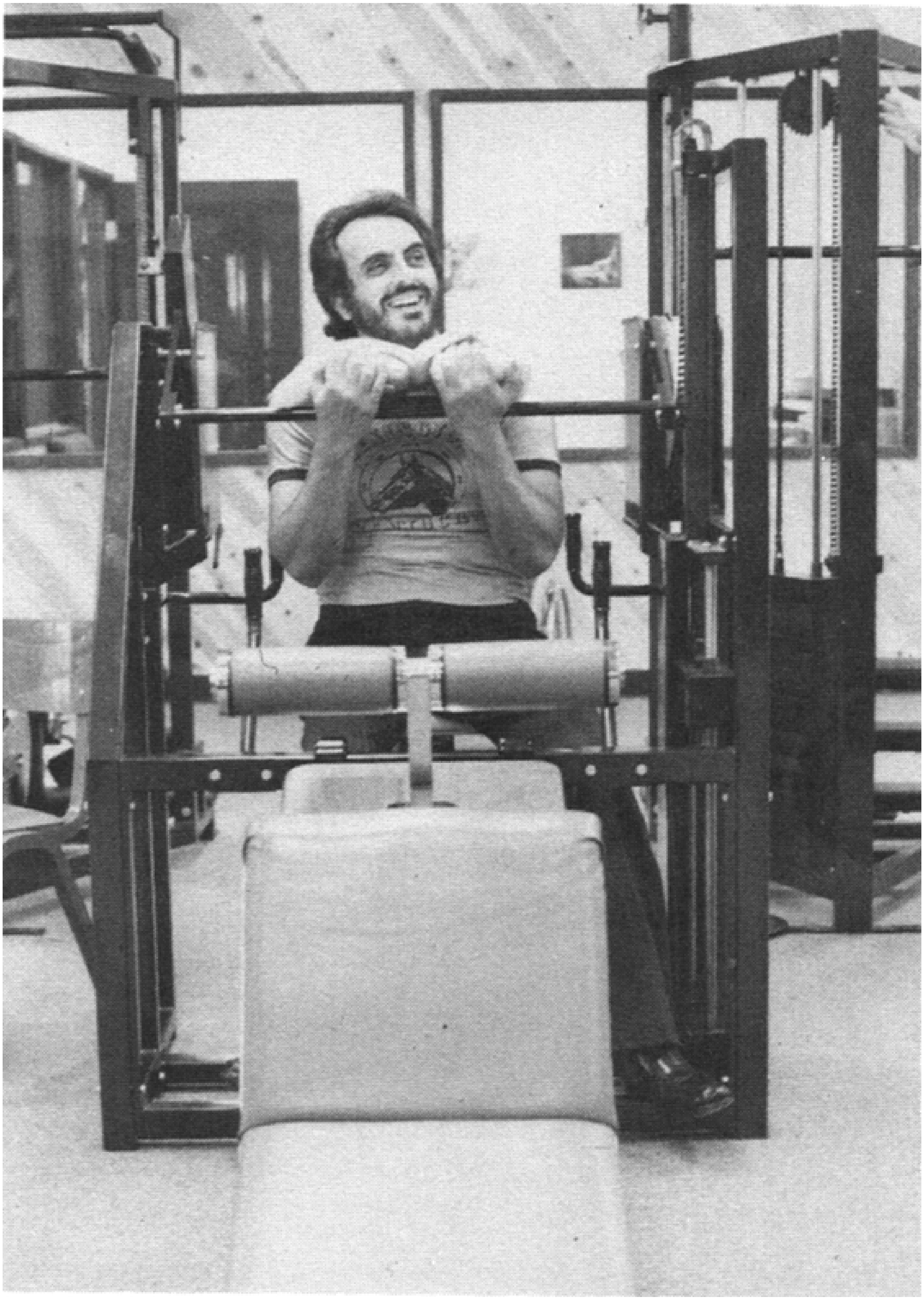
Johnson's up in Hollywood. I'm always up for a little action, nothing to lose, so I go up there. And they hired me right on the spot. And that's how I got into it. Nothing spectacular and no big plans to be a movie star. Just happened."

Was working in *Coming Home* a satisfying experience for you? "It was a satisfying experience because of the way the director, Hal Ashby, handled it. The way he let it be done is that every day we would go there, a scene was rewritten. We'd go for it as to how we thought the scene might be done; not Hollywood style, but true style. And it made a big difference. A lot of the dialog was ad-libbed. The opening scene at the pool table was like, OK guys, we're here, start talking about anything you want to pertaining to Vietnam. And we were able to do it."

Lou sometimes feels discriminated against within the film industry, especially when walking people get handicapped roles he feels he's qualified for: "I think what it is is that the public is not enough educated about people who are handicapped. The industry, being such a competitive industry, the man who's directing cannot take the risk of having someone give a poor performance because his livelihood depends on it too. But there's people like Hal Ashby or Jane Fonda, guys like Henry Winkler, Jon Voight; there's enough of 'em out there that if you keep plugging you're gonna get your breaks and eventually you're gonna be there."

Lou's interest in educating the public is not only professional. He serves on the Governor's Committee for the Hiring of the Handicapped, on the Executive Committee of the Wheelchair Basketball Association, and has a favorite vehicle of expression, which is through kids. He's a Little League baseball coach, and just became an assistant coach for a Junior All American Football League team.

"I love kids. They react naturally to what they feel and what they see. And in communicating with them, because I'm at the same eye level that they are, it's not Mr. Carello, it's Lou. I'm their friend. I'm not this big guy that's comin' down on 'em, I'm somebody they can come up and put their arms around and hug and feel good. The bond is just beautiful.



"But the thing that's really important is that by being around me, the handicapped person, they're learning about handicapped people at such a young age where they themselves, as they grow up, this will be something they will already know and be able to deal with, and they'll be able to pass the word along to their friends. So it's a way of getting the word out. Because a guy's in a wheelchair doesn't mean he can't coach us, doesn't mean he can't teach us. He's able to do all these things."

How has the injury changed your life? "I've become a softer person. I give more. I've become more in touch with my feelings. I'm more sensitive than I was before. I have more caring for people. I wake up every morning happy that I'm just waking up. And I'm sure that I have a different perspective on life because of my injury. So I live every day to the fullest that I can, and I'm happy just being here."

Is there sex after paralysis? "Sure there is. Sex, to me, is for everybody —it all depends on how you do it. There's *love* after injury. I think that's more important than sex."

6.4.5 Fred Rosene

If software engineering can be said to have a pinnacle, Fred Rosene is there. He's been with General Telephone and Electronics for 22 years, and can't seem to shake success.

"When I started there, I decided one thing I didn't want to be is a manager, and I've been a supervisor ever since one year after I got there. I move to get away from being a manager, and boom, no matter where I go, I end up as a manager. So I'm sort of resigned to becoming a manager.

"I've reached a point in my company that, whenever new projects come up, if I want them I can have them. A year and a half ago, I had four choices within one week that spread all the way from going to Italy to work, to going to Arizona to work, to working around here. I have offers all the time, so I really have total access to whatever I want to do within the corporation."

Sound like a grim commitment to the work ethic? Read on.

Fred is the only paraplegic I know who was injured on a toboggan. It happened in 1951, when he was 19.

"I was sitting in the middle, because I thought that was the safest, and I had my feet up around the guy in front of me. We went down the hill, over a bump, and that did it. I suddenly thought, Gee, this is what it feels like to be paralyzed."

He had nine more months to think about it at a Massachusetts hospital, where he experienced the minimal rehab common of the day. Then he went back to college. For a distinguished engineer, he took great pains to avoid becoming one: “My father went to RPI, and I did, and I didn’t like engineering. So I transferred to Tufts and ended up in engineering and didn’t like that either.” That was before his accident. Afterwards, he transferred to MIT because it was more accessible — there were two other wheelchair students there, which at that time was unique —and got his bachelor’s and master’s degrees in mathematics.

He still wasn’t ready to be a working engineer, and in truth, I don’t really know when he actually did become one. I do know that he became director of his church youth program.

“We’d set up a drop-in program for kids who are sort of dropping out of everything else. It was a group of kids heavily involved in drugs and all sorts of juvenile delinquency. What happened was that I was able to relate to them because they had to help me as well as me helping them. They had to help me down the stairs and up the stairs, you know, and it kind of worked out that it wasn’t just a one-way thing. Really, I think I was better able to relate to them than if I’d been able bodied and walking around.

"Somebody asked me to coach the church basketball team. I didn't know anything about coaching, really, but for some reason I said Yes, read a few books and I coached for 18 years. We ended up with a room full of trophies and we always ended up in the playoffs. We just had a good time. It was something it turned out I could do pretty well." It's interesting to note that one of Fred's first players was Bruce Marquis, ex-Executive Director of the National Spinal Cord Injury Foundation. Bruce claims that Fred showed him that wheelers were not only as good as other people, but better. Hmm.

During this time, Fred had long since become an engineer and project manager for GTE. He had also gotten into the peace movement. Can you be an engineer for a corporation with significant defense contracts and be a peace-nik as well? Fred could. He moved to a division of his company that had no military ties, then led a group of adults and kids from his church to Washington to participate in the Death March and the Mass March which followed.

To fill the gaps in his spare time, Fred does such things as serving on a city committee to help make the city more accessible. For years, he'd avoided disability-related projects because "I realized that just because people were handicapped, it didn't mean they had anything in common. I guess I reached a point where it didn't bother me to be involved in a handicapped thing. I'd accepted my handicap to the point where I didn't have to prove anything to anybody anymore."

And now, after 28 years of paraplegia, of coaching, counseling, committees and conscience, has he had enough? Nope. There are two teenagers here now, waiting for Fred to finish the interview so they can do the grocery shopping for this weekend's camping trip to Vermont. Fred's leading it. Seventeen kids from his church.

And between his job and church and ancillary activities, surely there's no time to spare?

"I've been fortunate enough to be able to make enough money to do basically what I want to do. I decided I wanted to skin dive, so I did that. I wanted to sail; I sail. I swim several times a week. I travel a lot."

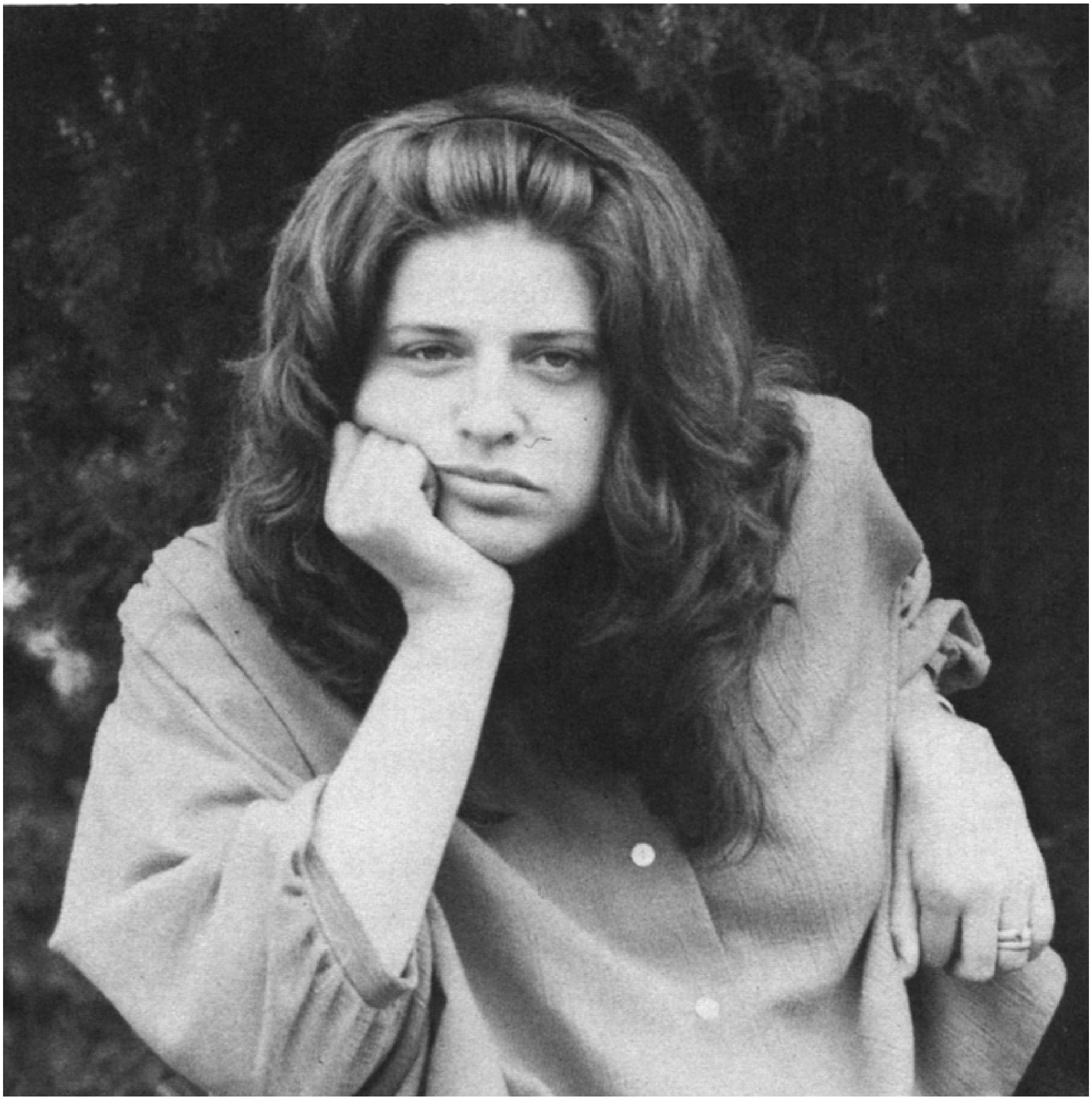
Have the 28 years ravaged his emotional and physical health? He admits to some depressed times during the early years, especially when he had to drop out of school to heal pressure sores. (This is an extremely common occurrence, and it's very easy for the novice gimp to think that it's always going to be this way. As almost everyone finds out, maintaining a cord-injured body is a learned skill that, once acquired, doesn't depart.) Fred describes his outlook and health for the last 20-plus years as excellent, as they clearly are today.

His new project? A three-wheeled motorcycle. At the age of 47, Fred's getting a dirt bike. For the hell of it. As he says, "There's a wheelchair motorcycle club, believe it not." Why not?

6.4.6 Nancy Becker Kennedy

She's mercurial in temperament, direct in demeanor and articulate as hell. Such a mouth, in fact, that this is a very easy profile to write. Nancy is so eminently *quotable* that she does it for me. Here's a little prehistory in a nutshell, because Nancy's going to take over right away. (Lest the foregoing makes her sound forbidding, she's not. She's warm, outgoing, witty, energetic and very funny. Just another Jewish girl running around in an electric wheelchair.)

1972. Nancy broke her neck diving when she was 20. C5,6. She did her rehabilitation, returned to college three weeks later, finished her BA, met her husband in graduate school, got her master's in broadcast journalism and moved to Southern California when Steve was accepted to UCLA's law school. She went to work in rehabilitation at Rancho los Amigos in Downey and he became a lawyer. It's now Nancy's ambition to get a job in broadcast news. That's all.



I asked a really intelligent question to start things off, which dissolved Nancy into gales of laughter: Did your injury bum you out?

“No! It was like getting a bad bag of grapefruit at the grocery. It was nothing. I just sloughed it off and went back about my business! (Emotional about-face.) No, it was terribly depressing. I mean, the idea you’ll become a social leper is not that pleasant to deal with. It was *such* a feeling of shock, I was delirious for three weeks. That was my way of coping with it.”

After three weeks, she asked her doctor whether she’d walk again: “When he said No, I remember putting my hand to my mouth and staring out a window and thinking, How can a person hear this and not blow up? How can you hear such a horrible thing in the world, and not fall off?” But…

“There were good points for me, like when I noticed an orderly in the hospital who was better looking than he had to be. And he was paying a lot of attention to me, and I even noticed that he was responding to my personality, and that made me remember that I was still a person.

"I had a very insane group of friends. They had me shooting this movie, *Deep Spoke*, while I was still in the hospital. It was about a woman whose clitoris was misplaced in the spokes of her wheelchair and she finds it out while getting a shoeshine. So they didn't make it easy for me to be depressed."

There were ups and downs, and downs generated by her ups: "Sometimes I would just trash out and feel like a zero, and think, Wait a minute. If you're being happy, it's just because you're not being realistic. Now get depressed again and get with it." Up and down…

"I said to one friend, Do I look just like a person sitting in a chair? He says, Oh, you mean instead of a cripple? And I says Yeah! And he goes, You look like Patty Duke rehearsing a movie for being a quadriplegic. You don't look like a real cripple. And I said, Oh thank goodness!"

Three weeks after she left the hospital, she was back in college: "Because I was thrust right back into what I was doing before, I was back on familiar ground. I was writing English papers again, I got my personality and wit back, and I functionally became very good because I had to type, I had to phone, I had to get things through for school." (She writes elegantly and fast, holding the pen vertically in the hinge of her hand. No splints.)

"So one big thing is to get back to doing things real quick, and the other is to be crazy enough not to lower your expectations one bit because you're in a wheelchair. I had this psychologist who told me: Love will have to mean less to you, religion will have to mean more to you, and work will have to take on a greater significance in your life. And I asked, What about falling in love? He said, Well, you'll have to direct your energies into other things. I said, Look, you're asking me to play probabilities because of my wheelchair. When you were in high school, somebody could have said, Look, you're skinny, you're not very goodlooking, you'll probably get married to a woman you don't think is pretty enough, and you'll be very unhappy. But you did a different thing. You became a psychologist and you wear suede jackets and you're real happy. You turned things to your advantage and I can turn things to mine.

"I wanted the same excitement out of life; I wanted an exciting career, I wanted to be in love, and, even though all indicators said I should forget it, I didn't. And it did happen."

So why, with a journalism background, did she go into rehabilitation work?

"The first thing I had a great compulsion to do was to get to newly injured people and tell them, *It's not what you think*. Because I really, when I was first injured, thought everything was all over. And my biggest fear was that I'd be socially ostracized. I kind of was carrying my prejudices against people in wheelchairs into my disability. And when I found out that I could resume my life and have as much pleasure, if not more, than I had before my injury, I felt a great need to get to newly injured people and tell them that."

Why, then, does she want to go into news? "I was an activist with concerns in all kinds of areas before my injury. I was active in the women's movement, the grape boycott, the abortion movement —I was even a socialist. I left some of these things behind, but I was basically just concerned with things being fair. So my desires for social justice are not just related to disability. I felt that news would satisfy me because I had 20 years of desires that pre-dated my accident that were not being dealt with by only doing disability-related work."

So far, she's produced a 28-minute film, *Wallflower: the Disabled in Society*, and has appeared —with extremely positive effect —on a segment of *Sixty Minutes* dealing with work disincentives. She's applied to two local stations, has been given encouragement, but so far, no job.

Nancy's marriage is obviously very precious to her. She starts to talk about Steve, marriage, in-laws; she's alive with enthusiasm and love and compliments, then she backs off because some things are to be experienced rather than spoken of. She's an irreverent woman, is Nancy, but some things command reverence.

Parting shot, for the librarian: "Some people don't believe in themselves for various reasons, and they think that the fun things in life are for somebody else. Nobody out there is any less of an asshole than you are. You can want everything they want. You know, don't feel insecure."

Such a mouth.

News flash: Nancy just got her job as associate producer at KCET News.

6.5 Words from the Wheelers

6.5.1 Wheelchairs

> "I think that there are two basic responses that people have to people in wheelchairs, one of them being admiration and one of them being pity. And if people are unable to overcome those initial responses, then they simply will never get to know you as a person."
>
> —Lyn Dickey

> "People's responses can be either really negative or really funny. It all depends on what your perspective is. I love to go out to a restaurant and watch people's reactions. People can be really turned on to you, they're really interested in what you're doing, and just watching facial expressions is priceless for me. To me it's funny. Some people will be turned off by it. I get into it."
>
> —Rick Harry

> "I wasn't a really outgoing person. I guess the people in town were afraid of me at first, but people talk to me now. They ask me what happened to me, so I'll tell 'em. Now I'm used to it. They got used to me. Now they stare at me and smile and I'll smile back. Nice."
>
> —Deanna Gonzalez

> "The wheelchair is a very, very good place to observe life from. From that wheelchair, you can see so much of people, and they will tell you so much about themselves."
>
> —Larry Quintana

> "With the quads, in particular, in our sports program, there's almost a reversal of situations. Their spouses, friends, attendants, whatnot, develop acute chair envy when we're at the Games. They want to be in chairs themselves. Everybody there is so united in their intent, and having such a great time doing it, that other people want to get in a chair and race around."
>
> —Mary Wilson

> "This chair doesn't mean anything. It doesn't affect anything except the ability to walk. I roll places instead of walking. Sometimes I roll faster than people can walk."
>
> —Steve Epstein

> "When I sit down at a table with somebody, they sit down at a table too."
>
> —Rob Lewis

> "Living as a spinal cord injured individual is really no different than living as an able bodied individual, except that you're doing it on wheels. Some of the technical aspects of living on wheels are different."
>
> —Elmer Bartels

> "It's done one good thing. People always remember me"
>
> —Fred Rosene

6.5.2 Feedback

"Recently, someone asked me —it was an Indian — Are you ever going to walk? I says, No, man. He says, Oh come on. You are. I go, It doesn't bother me. I hope I do. It'd be kind of nice someday. But it doesn't really bother me, so don't let it bother you. Don't let it get you down."

—Larry Quintana

"Most people that you meet do not understand that there could be any conceivable reason why you might want to be the person you are. If disabled people can see themselves as being worthwhile and being able to do the things they want to do and can convey something of this to others as they go through life, it will have an effect not only on other disabled people, but on the expectations of the public. And that, after all, is what opens the doors to us when we go to look for jobs, when we seek positions on advisory committees or in political situations or volunteer work. It's public expectations which, to a large extent, determine what you can do. And we have some responsibility for changing these."

—Judy Gilliom

"If any disabled person is honest with himself, the life we had before we were disabled wasn't all that golden. If we got back to it through some Fairy Godmother, would we be completely happy, whole, healthy people? Able bodied people are not cosmically healthy."

—Binny Clark

"I'm a counselor —I have that role. I'm an unmarried counselor, so consequently, I'm out beating the streets looking for women. I'm in the dating scene. I'm a young person. So I have a lot of different roles. There are a lot of different possibilities for our involvement with life—we're not just relegated to one particular role as a disabled person. And all these different people coming in from different lifestyles are making disability a real thing. It's not being a poor little poster person on a wall somewhere, *it's livin'. It's a lifestyle!* And there are a lot of different lifestyles because there are a lot of different people. I think that's changing people."

—Rick (now married) Harry

6.5.3 Dreams

"In my conscious mind, I never say to myself, Gee, I wish I were walking. In my dreams, I'm doing things, without pain, I'm sometimes making love, and I'll get up in the morning and be extremely depressed. Maybe the most depressed moment of the day is when I wake up from a very happy dream."

—Frank Musinsky

"I had this really perverse dream where I was up walking around. It was in my hospital room and I was doing things. Then the nurse came in, so I jumped back in bed and then got out again when she left. Most of my dreams, I'm not hurt. Some dreams I can't do — there are things in it that I can't do and it puzzles me, usually. It's like a vague reminder, not a crushing blow."

—John Galland

"At first, I was always running in my dreams. Then I slowed up, then walked with difficulty. Now I'm aware that I'm dreaming, and I'm still walking with difficulty, but I realize, I mean I *know*, that the dream is real and that the other reality in a wheelchair is a dumb charade. It's not really depressing. It's not really elevating, either."

—Barry Corbet

"Midnight shakes the memory
As a madman shakes a dead geranium."

—T.S. Eliot

6.5.4 Kids

“If anything, my injury has brought our family closer together, because before the injury I was so wrapped up in the little games the business world plays that I was seldom home and I didn’t really see my kids growing up. And after getting slowed down enough to where I could be around home, why, it’s a unique experience to get to understand what your kids think and why they’re thinking this way and getting their side of life.”

—Bill Smith

“Kids are the most honest people. And kids, once they get over their initial curiosity, have no problem with people in wheelchairs. You wonder why adults can’t be like that, why we lose some of that childhood innocence and intelligence.”

—Steve Epstein

“Sometimes they can bug you to death, and they can really make you crazy if you let them. But all you have to do is grab them and put ’em in the chair and give ’em a ride, show ’em a couple of wheelies, and you have ’em for life. They’re your fans forever. I think probably the most exciting thing to the kids in the Crested Butte school is my wheelchair. They just think this wheelchair is really neat. And since I have a spare now, I’m going to send the old one down to the school for a few days and let the kids learn about wheelchairs.”

—W. Mitchell

6.5.5 Travel

“Just before I go, I don’t want to go because I don’t know what’s waiting for me in San Francisco. But I’m awfully glad I go to San Francisco. So it’s just overcoming that initial fear.”

—Rob Lewis

“I just came back from the Trust for Historic Preservation meeting in San Francisco, where I was asked to speak. I was in Indianapolis a few weeks ago speaking to Park Directors, trying to inspire them to make the parks more accessible to all our citizens. Today, I’m in Denver talking to the Mayor’s Committee for the Physically Handicapped. Then I go to Albuquerque on Friday for a meeting on neighborhood energy conservation … and then to Washington to testify before the House Interior Committee … and I come back here keynoting a talk in Denver on the twenty-sixth, and hope to get re-elected in Crested Butte on November the sixth, otherwise I’ll be in trouble.”

—W. Mitchell

“I flew into the Colorado Springs airport and my wheelchair was not on the plane with me. And I waited for the next two airplanes to fly in, which were the last two of the day, and my wheelchair was not there. And so I did see this old beat-up airport wheelchair and asked the fellow at the desk if I could use it until mine arrived. He told me he couldn’t let me do that because he felt he ought to leave it there in case somebody needed it! Well, I think that’s funny.”

—Lyn Dickey

6.6 Lives III

6.6.1 Anna Absalom

The house is green brick, situated in an old, well-kept neighborhood, and looks inhospitable from the front. Stairs. Lots of them. Around to the alley. Better. It's pretty much like anybody's back yard: parking apron, high fence with gate, trash cans and a path leading to another set of stairs. But there is also a door at the ground level, and Anna appears at the upper door. She'll be right down.

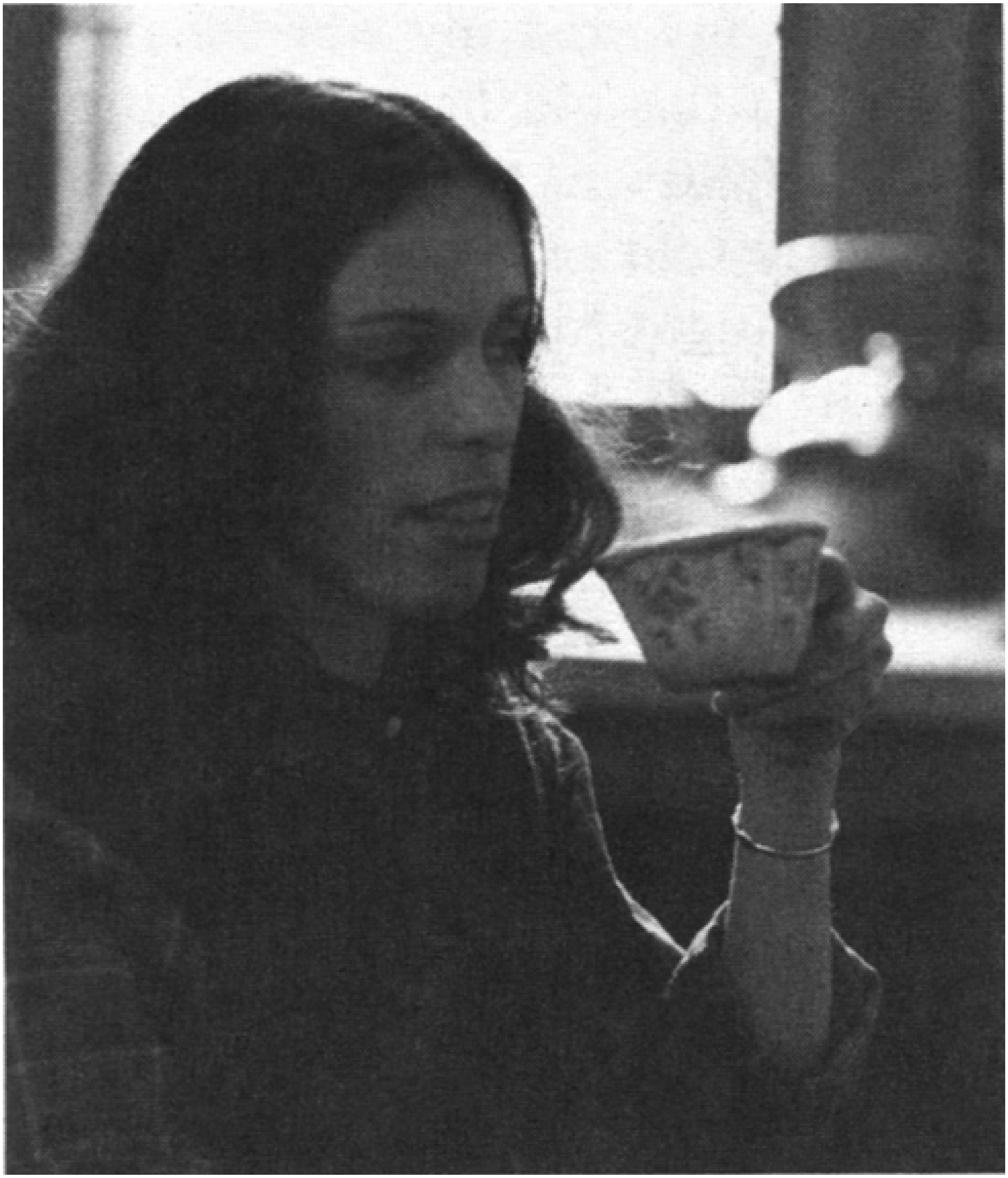
She is. There's the unmistakable whoosh of air that accompanies a descending elevator, and Anna asks us in. The room feels good in some vague way, although it is actually an afterthought created when Anna obsoleted her garage by buying a van too high to enter it.

The elevator is exactly large enough for the wheelchair, and I ride up first, sending it back down for Anna. This gives me a minute to take the place in. It is incredible. The elevator opens onto the kitchen: old brick, arched window lintels and a venerable drop leaf table that looks Quaker to me just because it's classically simple and beautiful. That's the old part. The new is a wheel-under sink and stove, lowered counters, raised oven and a dishwasher. All very modern, all exquisitely compatible with the surrounding antiquity.

Anna arrives and we move to the living room. There's some principle of design and taste operative here that I don't yet understand. I see three or four more pieces of extraordinarily honest and appealing early American furniture, including two Windsor chairs, in a room of light and openness. Instead of using limited space to show off lots of objects, she uses a few objects to show off lots of space. Bare off-white walls, bare wooden floors, yet not a trace of austerity.

If clutter is to be found in this house, it's in the workroom adjoining the living room, and it's very functional clutter. One entire wall is covered by a complete color spectrum of hanging yarn. A corner holds a large slanted work surface illuminated both by overhead spotlights and magnifying goosenecks. There's a Scheffelaria plant to separate business from frivolity, and a spinet piano occupying the last available wall.

Upstairs are the bedrooms for Anna and her two daughters, also reached by elevator. Anna tells me it's a pleasant open loft, and I don't have to see it to know that it's exceedingly pleasant. You could say that I liked Anna's house.



Why, I wanted to know, did she ignore the splendid dissenting advice from the rehabilitation center and from experts, including me, to get this funky old three story relic where she had to build an *elevator*, for God's sake, just to get home? Why not get a nice efficiency apartment with security, central air conditioning, wall-to-wall carpet and a four-by-six balcony with a view of more balconies?

The question is fully answered just by seeing Anna at home in an environment of her own making. But since we can't all visit her, here's why: "I've never lived that way. I didn't want to start. My parents had bought this house as a rental property, and a friend of mine made a videotape of it and brought it to me in the hospital, and I said *that's it*. I did look at some things that were on one level, but it would have been a lot more money and I didn't see anything I really liked."

Before her hospital discharge, she paid a visit to Gerry Winters, a quad whom Anna had been told had designed a really excellent house. "Just seeing her there was so inspiring because she had raised these four kids and she had this beautiful home and a good marriage and it was just really nice talking to her. Talking to her was the most influential thing that happened."

So Anna got her funky three story house and found it to be good.

In 1975, a month before her thirtieth birthday, Anna became a T12 para when her VW beetle blew off an Idaho highway. Her second marriage was failing and she had two young daughters to care for. She had a BA in English, a California teacher's certificate, part of a master's in art history, a strong interest in ballet and, most important for her financially, she had received extensive training in the craft of weaving from a French Canadian master who had taken her on as a private student. She makes her living reweaving textiles, mainly oriental and Navajo rugs, and has been doing it for over 10 years.

"I never thought I could continue to do it for a living, but I have. It's just worked out that way. I started working for a few dealers here in town, and of course dealers always have things that need to be repaired. And then I met a few collectors, and collectors always have things also. I mean, they're always buying other things, and then they gave my name to friends. And I've done work for some museums here, and they give my name out. The other thing I've got going for me is that I don't have a lot of competition. There aren't too many people doing what I'm doing."

Indeed there aren't. "Reweaving" is not an adequate word for what Anna does. Her work requires a knowledge of dye chemistry, an understanding of many weaving techniques traditionally used by the cultures which originally produced the art works she repairs, and an uncanny ability to match color, texture and design. She's very good at what she does and has all the work she wants or needs.

Then there's another role, Anna as mother. Her quick shot about teenage kids is that they're "real maddening." But … "I wouldn't have been able to move into this house as soon as I did and get everything going if I hadn't had them here.

And they’ve been really helpful. I guess that it’s a sign that everything has returned to normal that now, if something needs to be done and I ask them, they don’t always just rush to do it. In the beginning they sort of waited on me and acted like little nurses, and now they just act like normal unruly teenagers.”

Socially, she does about as much as she did before the accident, going out to dinner, movies or performing arts, or visiting friends. Intimate relationships are more of a problem for her because “People don’t know what to expect and they’re afraid to ask and they’re afraid to find out.” She has not run away from intimacy, just finds it a difficult subject that needs attention.

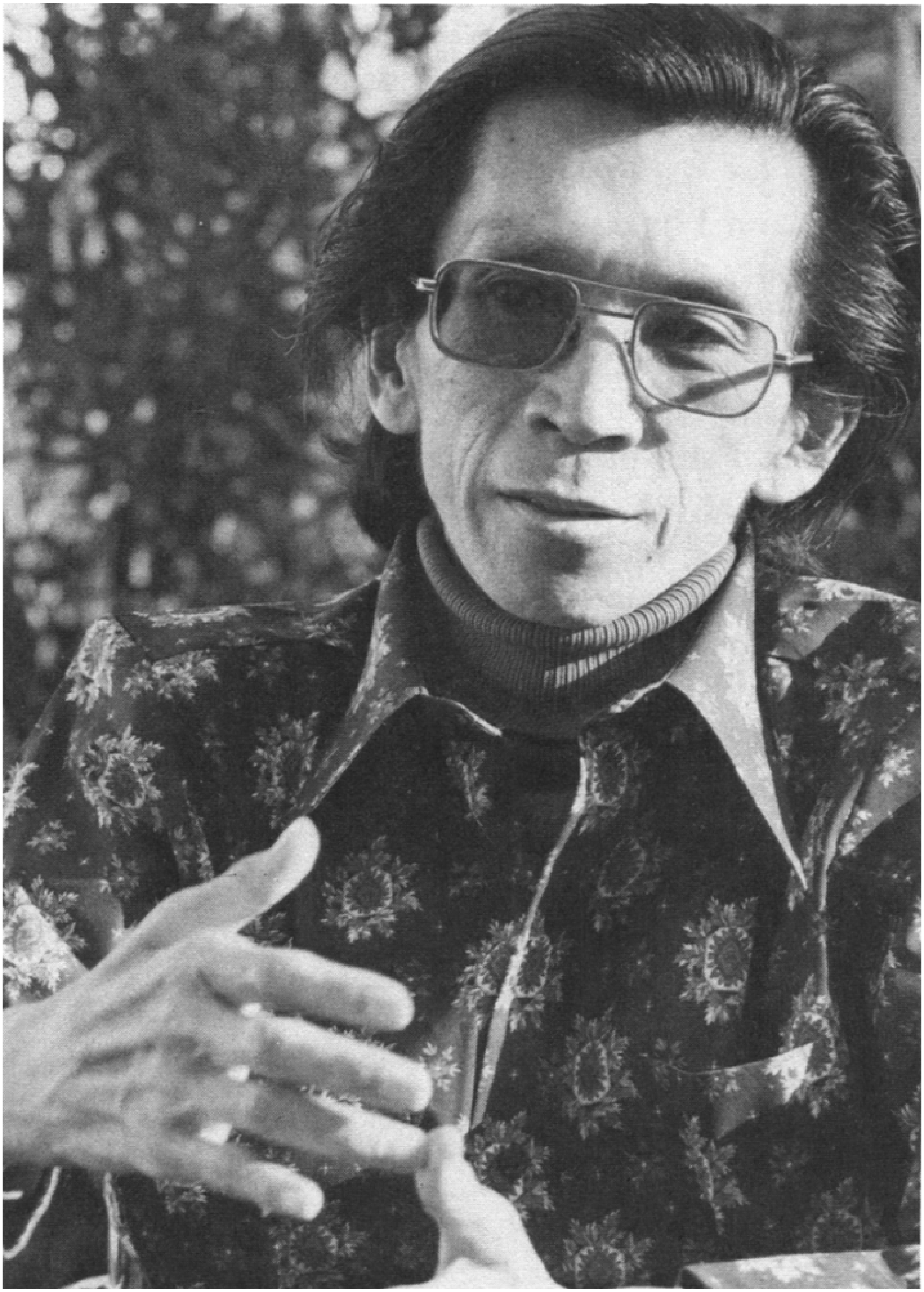
“Yes. It’s different. I feel it’s not a totally explored area for me yet. I’d have to have a long time with somebody, and I haven’t.” She will. Today, she speaks enthusiastically of a relationship that started some time ago…

In the meantime, she performs her exquisite craft in her exquisite house and feels that life is OK. “I think basically that I still have the same problems that I always had, that if I really try to look at the reasons for my problems, the accident isn’t the main one. It might contribute, it might influence the way people look at me or the way I look at my life, but I don’t think I can blame my problems on that. Well, some of them I can—the fact that it takes me 15 minutes to get my socks on (laughs). But I don’t think things are really that much different.”

6.6.2 Tad Tanaka

Tad’s a product of a first and second generation Japanese family, a high school education well suited to an agricultural life in his native San Joaquin Valley but to very little else, and an independent spirit. By the time he was 13, he was working part-time. By the time he finished high school, he left his family home in Fresno. As a final act of independence, he bought a motorcycle. And then he tangled with a car and broke his neck. C7. It was bad timing all around, because he’d just declared his independence in a fairly rebellious manner and now faced years of extreme dependence, and because the year was 1949, the town was Fresno, the available expertise was minimal and nobody around him was rich or particularly well connected. Tad was trapped.

And this is a 30 year escape saga.



If any object describes Tad Tanaka, it's the well tended garden, about one foot by two feet, which sits on the kitchen table. It's a monument to a fastidious nature. So is the mobile home he lives in. Every room is tiny, meticulously planned and very serviceable. No space remains unused and no space overflows. Most of us have taken pleasure, especially as children, in making small spaces fit our needs exactly. Tad's trailer is a good fit; sculpted utility. The only large object he owns is a Buick Riviera, and the only things that have gotten out of his control are his books, which spill out onto all available surfaces. This is because he's a compulsive reader and because he's getting ready to move about 200 feet to a larger trailer. But not everybody who's cramped for space admits to having 20 years of *Scientific American* hanging around…

We're in Paramount, California, about an hour's drive south of Los Angeles, talking about the way it was in 1949.

"I can't say that I went through a rehabilitation experience at all. I think it should be remembered that things were pretty primitive all around. Education, rehabilitation, everything. When I compare the services available now with the services available then, there's a huge difference. So I had no opportunity, really, to do anything. The automatic transmission was just coming out, right? That means you had to buy a *new* car if you were going to drive. Well I didn't have that kind of money. And for that matter, I didn't even know a quad could drive. There just weren't the organizations to inform you about anything."

Tad started in a Fresno hospital, and quickly developed a huge pressure sore. The hospital knew no more about the cure than the prevention, so he spent five months at Saint Mary's in San Francisco patching up the damage the other hospital had inflicted in only six weeks.

Healed and forewarned, he returned to the Fresno hospital, then was discharged to his parents' home. Since he had severe spasm, he gave the Fresno doctors an opportunity to experiment with some novel ideas. They kept him in bed, with leg braces on, for two years. The idea was "to stretch the spasm out." After two years of unremitting spasm, he went back to San Francisco, had a tendon release, and his spasm was gone. Back to his parents' home. Essentially, he spent the first three years after his accident in bed.

One good thing did happen at Saint Mary's. "They put me in a five bed ward where they were all spinal injury, and that is where I started learning about other disabled people and how they lived. My attitude changed drastically —that wasn't bad."

But he kept coming home to Fresno. "I spent a lot of time trying to figure out what to do. Of course a lot of my time was just killing time, you know? I was looking into what kind of business I could operate from the home." He was also reading a lot. His interests became much more intellectual, and he found himself drawn to the sciences and philosophy and eventually to psychology.

He developed a business selling stamps to stamp collectors, which brought him about $100 a month. But it looked like a dead end, something that would never fully support him. And he had these new interests emerging, and California, at that time, was coming in with their Aid to the Totally Disabled assistance, along with funds for attendant care. So he applied to DVR for schooling assistance. He was refused. They told him that he already *was* rehabilitated, he had a business going, and if he wanted to improve his situation he'd have to do it on his own. (It's ironic that Tad is now a member of the State Rehabilitation Advisory Committee.)

He reviewed his options. Here in California, the land of gold plated personal injury liability settlements, Tad was awarded a magnificent $4,000, of which the lawyer took the top one thousand. In addition, the car's driver was found guilty of negligence and fined $15. The state got that. So Tad took his $3,000 nest egg, augmented it with a scaled down version of his stamp business, bought a small second hand trailer, moved out of his parents' house and enrolled at Fresno State in the spring of 1964. Without DVR. To keep it all straight, that's 15 years after his accident.

At Fresno, he co-founded a local chapter of the National Paraplegia Foundation, his first step into advocacy. He also decided that Long Beach State better met his needs, so he moved, mobile home and all, to Southern California. By 1971, he had his degree in psychology. In 1972, he began a services program for disabled students at Long Beach. "Sort of by accident, my interests turned in that direction. And then I discovered an opening at Cypress College, I applied for that and I got it. So I've been working with disabled students ever since." He helps students recruit attendants, find financial aid and work their way through the jungles of red tape surrounding all government services.

He's also a rights activist. He's a board member of the Dale Mackentosh Resource Center because it is located in Orange County and therefore serves his students. He's a board member of the West Side (West Los Angeles) Community for

Independent Living because that group is deeply involved in the effort to eliminate financial disincentives, a subject of particular concern to Tad. In 1976, he was one of the 16 elected delegates from California to the White House Conference on the Disabled. While in Washington, he dropped in on HEW to talk about welfare reform and made useful contacts with several legislators. He was back again in 1978, this time fighting disincentives. He has served the disabled very well.

Plans? He wants reduced advocacy activity, so he can read and recreate more. He's moving to a two bedroom mobile home, not because he wants more space, but to ease the day when age might require him to have a live-in attendant. He thinks ahead a *lot*.

What has he learned during the last 30 years, other than that things have improved? That Regional SCI Centers and Independent Living Programs, with their wide range of services, are the best things that have happened to the disabled. That when in doubt, ask another disabled person; they're the ones who know the most about solving problems and getting things done. That activity *is* life. "Especially in this area, there are so many things that a person can be active in, even a person who's severely disabled. That's the key: talk to other active people, get some ideas about what's going on—there's just hundreds and hundreds of things that you can get into. You can pick just about anything you want to."

6.6.3 Don Scanlon

Doctor Don Scanlon has a wonderfully open, sensitive face, and a constant flow of humor that intermingles subtly with a lot of sincerity. He is bemused not depressed, when he speaks thus:

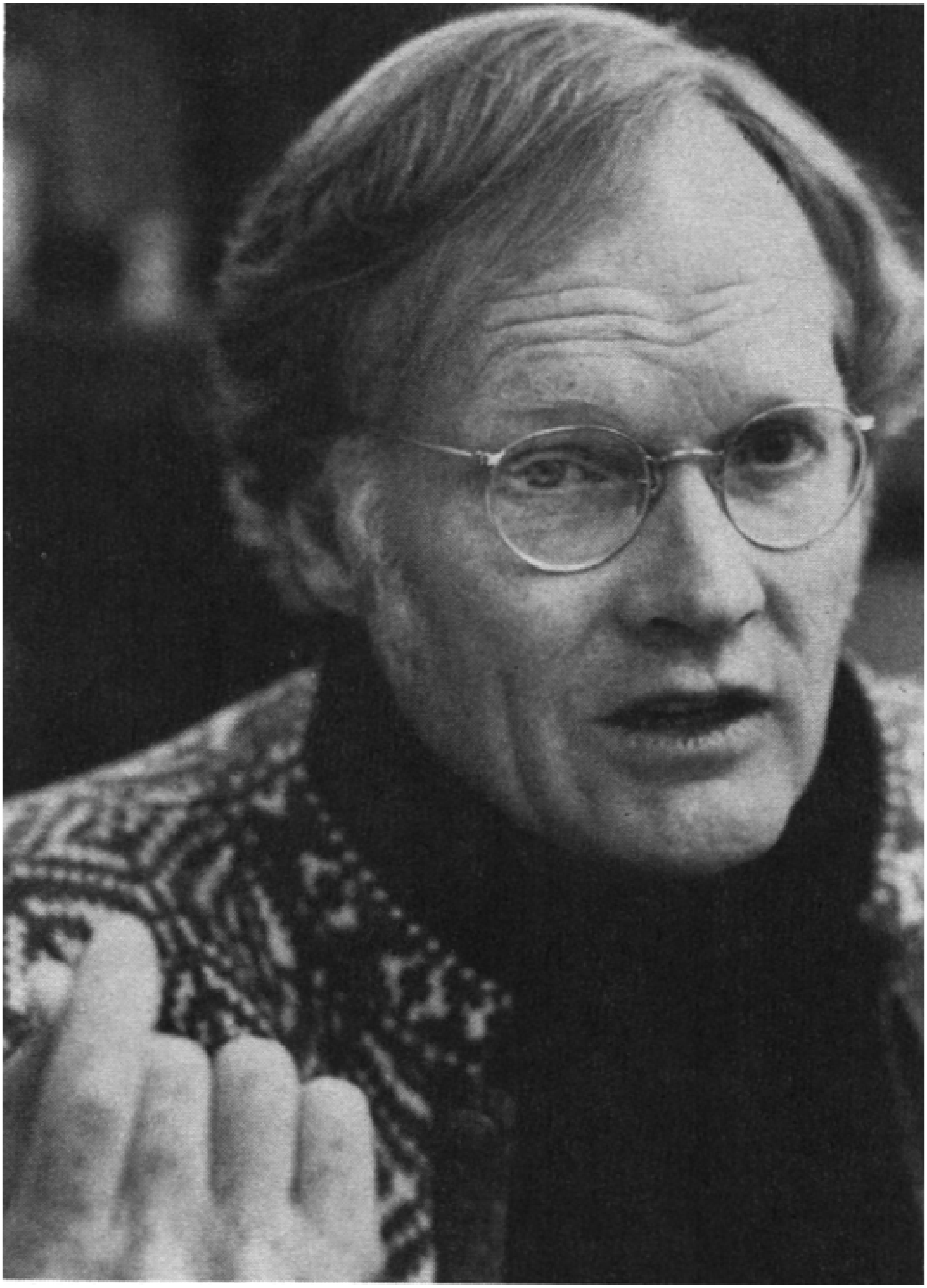
"I like to read. I've found myself, over the years, fascinated with books about prisoners. Solzhenitsyn and those things. And I used to think, God, I'm so fascinated with these things that I'm going to end up in prison some day. But I'm such a model citizen that I never could understand how the hell I would get into a prison, you know. So I thought, well, there's nothing to that. Then one day after I'd been injured, I thought, Jesus Christ, look at what you've done. You've got yourself in your prison!"

Don not only got sent up for life; he got the electric chair. But not to worry —this is not a morbid tale. This is the happiest story of complete and rewarding rehabilitation I know.

In 1976, when Don was 46 years old, he had lived in Carmel for 15 years, was an internist in private practice and the Chief of Staff of the Community Hospital of the Monterey Peninsula. He had four daughters and a strong interest in the mountains and outdoor sports in general. While bicycling with his daughter he caught his front wheel between two boards on a small wooden bridge, went over the handlebars and torpedoed to the ground. I asked him how a doctor feels when diagnosing his own paralysis:

"There was a lot of denial. I was lying there on the ground and I was thinking —I wonder how long this is going to last? I'd like to get up and go on home. I knew that I'd broken my neck, but I really did not understand that this was QUADRIPLEGIA, and that this was what it was going to be from now on."

He spent a month at his own hospital, then four months at Santa Clara Medical Center, one of the Regional SCI Units. While Don worked on his rehabilitation, his community worked on getting him back. The hospital, within days, had made personnel changes, found accessible office space, and created a new job for him. He also got a job offer from Santa Clara's Rehabilitation Division (then run by Glenn Reynolds, a post-polio para). Making a living clearly wasn't going to be a problem.



Don is now the Director of both the Cardiology and Medical Education departments of his old hospital. He has what he describes as a quarter-time private practice, with an office in town, but spends most of his working hours at the hospital. His office there is small and crowded, with a few minor design modifications for the wheelchair. There's a panorama of Mount Everest and surrounding peaks, and it turned out we'd both been there before our accidents. I asked him how his professional life has been changed by the chair.

"I'd say it's had remarkably little effect. For awhile there was the problem when I would see patients, with them feeling: Gee, I really can't tell you my problems, Doc, and your problems are so much greater than mine that mine are nothing. That created a little bit of a barrier to communication for awhile. On the other hand, in some instances, it's given me a tremendous entrée. I can go into a room of somebody who's had an injury like this, people who've had strokes or something, and immediately talk with them. And they know that I know pretty well what they're going through."

Does he feel any limitations as a doctor? Not many. As a C5,6, his hands aren't sensitive enough for some aspects of physical examinations. He doesn't make house calls very often, but he has made a few. He has recovered enough thumb movement in one hand to hold a fork or spoon or write without a splint. "I just put the pen down between these two fingers, and I can write pretty well. You know, a doctor doesn't have to write *too* well; he's got a reputation to uphold. I write better than most of my colleagues." And with an infectious grin, he reports his ability to slip his hand down over the neck of a wine bottle and drink from it, a matter of real importance.

He clearly feels comfortable with his own competence, but what about medicine as a schooling objective? "I've thought about a young person wanting to go through medical school as a quad. I wouldn't say it can't be done. Probably it has been or will be done, but I must say I'm glad I don't have to do that." Nevertheless, he does know of cord-injured psychologists, radiologists and psychiatrists who have received their training post-injury. And there's the dermatologist in Santa Cruz who works from an iron lung…

About new injuries: "A person takes into SCI whatever he already is as a person. If he's sour on the world, he's gonna have a hell of a time. I don't exactly know what that person needs to do, or I can't tell him what to do, other than to somehow accept what he's got and realize that this is just one more problem of life. It's of a different sort, but I don't even think it's worse, in a way, than the problems that everybody else has to face. We always manage to bring our problems up to the level which is the most we can stand. If you don't have enough problems, if there aren't enough problems provided in your life for you by the way things are going, you'll create them just up to however much you can take. Right up to the brim. Spinal cord injury, that just relieves you of the responsibility of providing those problems."

How about SCI and aging? “I think, look at what I’ve gone through already, and it’s worked out some way or another. And it will when I get older too. No, I don’t worry about what’ll happen when I get old.”

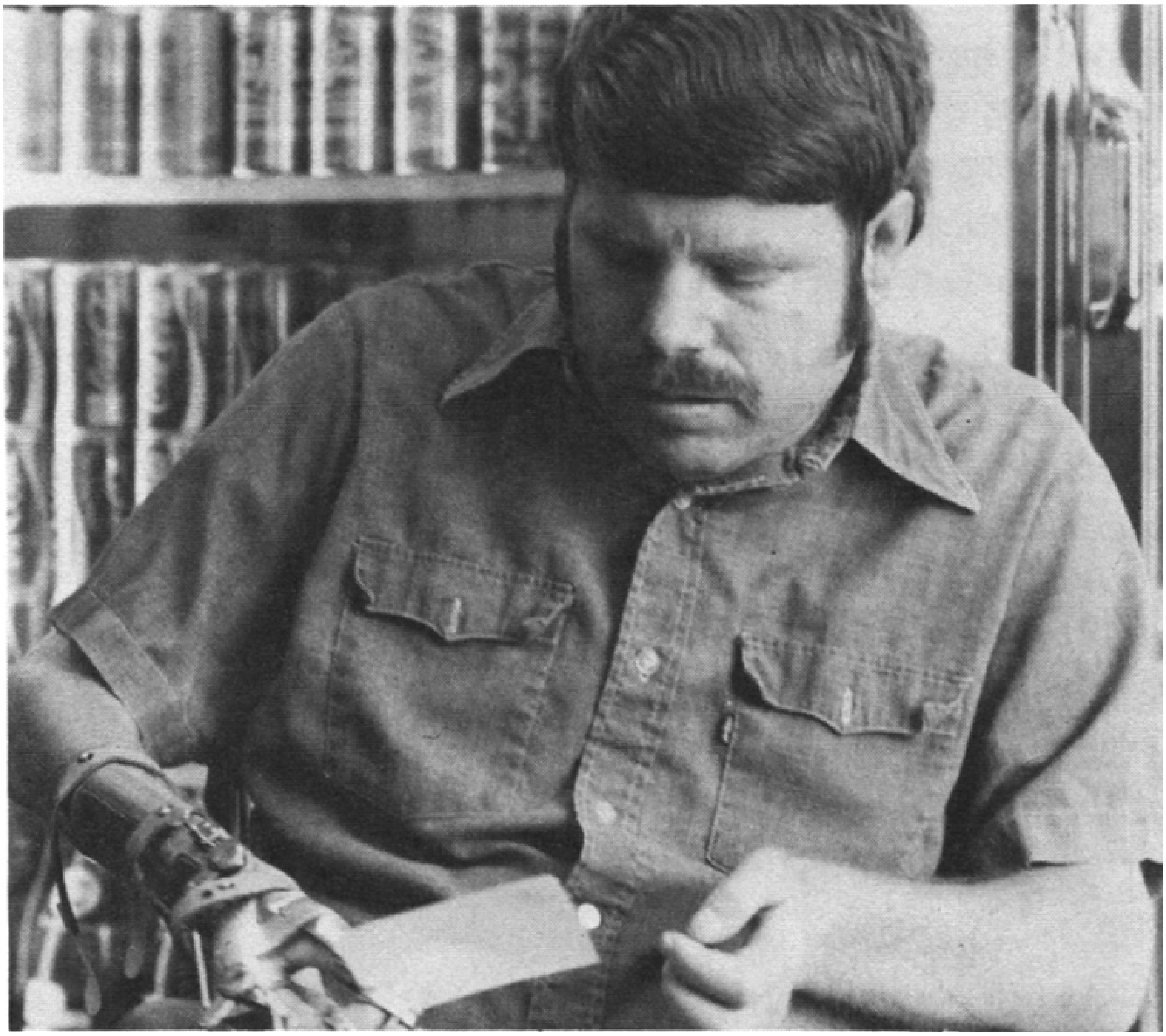
And about his prison: “I just don’t feel imprisoned anymore. Something’s happened, and I don’t feel that way anymore. My life has expanded; it’s wonderful. I really live a full life, a good life, a rewarding life, a fulfilled life. Neat things are happening to me all the time. They have been especially ever since this injury. I’ve never seen or experienced such an outpouring of love from the people in my community. It’s magnificent. That’s not to say there are no problems, but it is to say that in the presence of those problems, life is, for me, better than it ever has been.”

I hear a lot of hype from wheelers who exude cavalier statements about how SCI has improved their lives, and generally disregard it. Don Scanlon’s not saying that his injury improved his life, but that he improved his life while simultaneously coping with a potentially devastating injury. That’s very different and very real. It’s a wonderful thing to see. I don’t inspire easily, and I’m unabashedly inspired.

6.6.4 Bob Bowen

In 1963, Bob Bowen had just finished high school, was working on his father's ranch in Missouri, and was looking forward to being big in the sports scene at Texas Tech the next fall. He'd already been accepted for admission. He was breaking a horse for his sister when he was thrown, which gave him a C6,7 fracture. This however, is not the hard luck part of the story.

Bob's injury was incomplete, and he was soon getting around well on crutches and short leg braces. He got in several semesters at Texas Tech, worked at times on the ranch, got married and was doing fine when his family traded for a new ranch near Chadron, Nebraska.



It was in 1970 that Bob's luck turned sour. His paralysis started getting worse, and nobody knew why. For someone with an acute awareness of the consequences, progressively advancing paralysis must have been a demonic bummer. He had two traumatic and unsuccessful operations to halt the paralysis before he went to Craig. A neurosurgeon found a large cyst formed on his spinal cord, drained it, and successfully stabilized his condition. But by that time, he was a complete quadriplegic. This was pretty disheartening — so much so that it broke up his marriage. "We were both scared, my wife and I, and neither one of us was willing to put out what the other needed at the time." So with no wife, no job and very little physical function, Bob had to make adjustments that made his original accident seem trivial.

"It's a case of, here you're sliding downhill, and you almost have to hit bottom. Then something kind of wakes you up and shakes you and says, Well, what are you gonna do? It can't get any worse. You gotta start building from here. You finally gotta someday wake up and realize that you're goin' to hell and if you don't straighten your act up, you're never gonna do nothin'. So you just start from there and go.

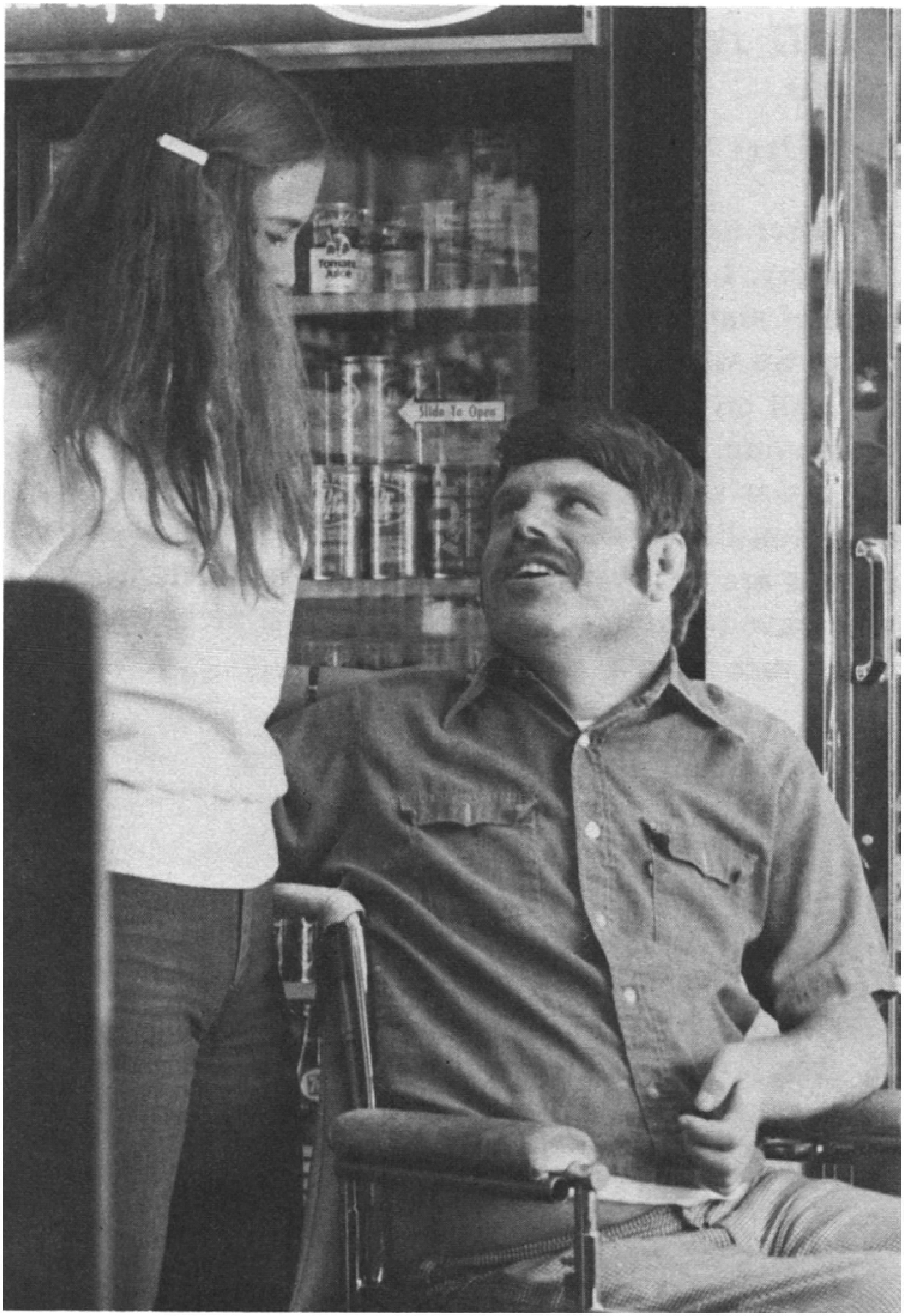
"Getting out … it's hard to re-establish yourself. You almost have to start over from scratch. You've really got to make up your mind that you want to make it."

He decided he wanted to make it, then he figured out how: "Finding jobs is difficult, especially in a small town like Chadron. And I just decided that if I was gonna get on my own and be able to work and make a living, I was gonna have to create my own job. So I bought the liquor store and became my own boss, and it worked out well for me. I've found that I can compete in the business world, and the chair doesn't make any difference at all."

The store has done well and so has Bob. As we talked in his house, friends dropped by to chat or invite him out. Employees in the store have a close rapport with him, and he's obviously well liked in his community. Part of this ease of communication must come from the fact that he has never felt adverse public attitudes directed at him—earlier, on crutches and braces, and now, in electric chair and hand splint. He doesn't worry about how he appears to other people. They can worry up a storm if they want to, but that's *their* problem.

What other businesses could a motivated gimp get into?

"I really don't think you're limited. Naturally, you can't get into something that gets into a lot of physical labor. But here in Chadron, I could manage the Gamble's store or run a filling station. I could go operate one of those three or four hundred cow ranches, if need be. It kind of depends on what your background is and what you like to do. If you like to do it, you're not limited."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TOMATO JUICE

Bob obviously doesn't feel limited. He's sold his liquor store, bought a house, and plans to finish his business degree. After that, he's thinking maybe he'll get a real estate license or go on for a master's degree in finance so that he can become a stockbroker. In the meantime, he'll support himself with the proceeds from the sale of the liquor store and a small gun business which he'll run from his home. (He used to own a gun store, and still holds a federal firearms license. He sends out a gun catalog which is imprinted with his name. This allows customers to order through him, using his license in effect, without requiring him to handle merchandise directly.) And if none of these things should appeal when the time comes, Bob's got a head full of alternatives he's confident will work.

Personal relationships? He feels they've become deeper: "It seems it works out better. You're more sincere about each other. I've had a lot of beautiful relationships since I've been in this chair."

He also has no problem with attendants, although he doesn't like the word because he feels it's demeaning. He gives college or local working kids room, board and utilities, but no pay. Bob tends to think of his present attendant as a brother, and it's the mutual respect that makes it work. He's never had trouble finding good people.

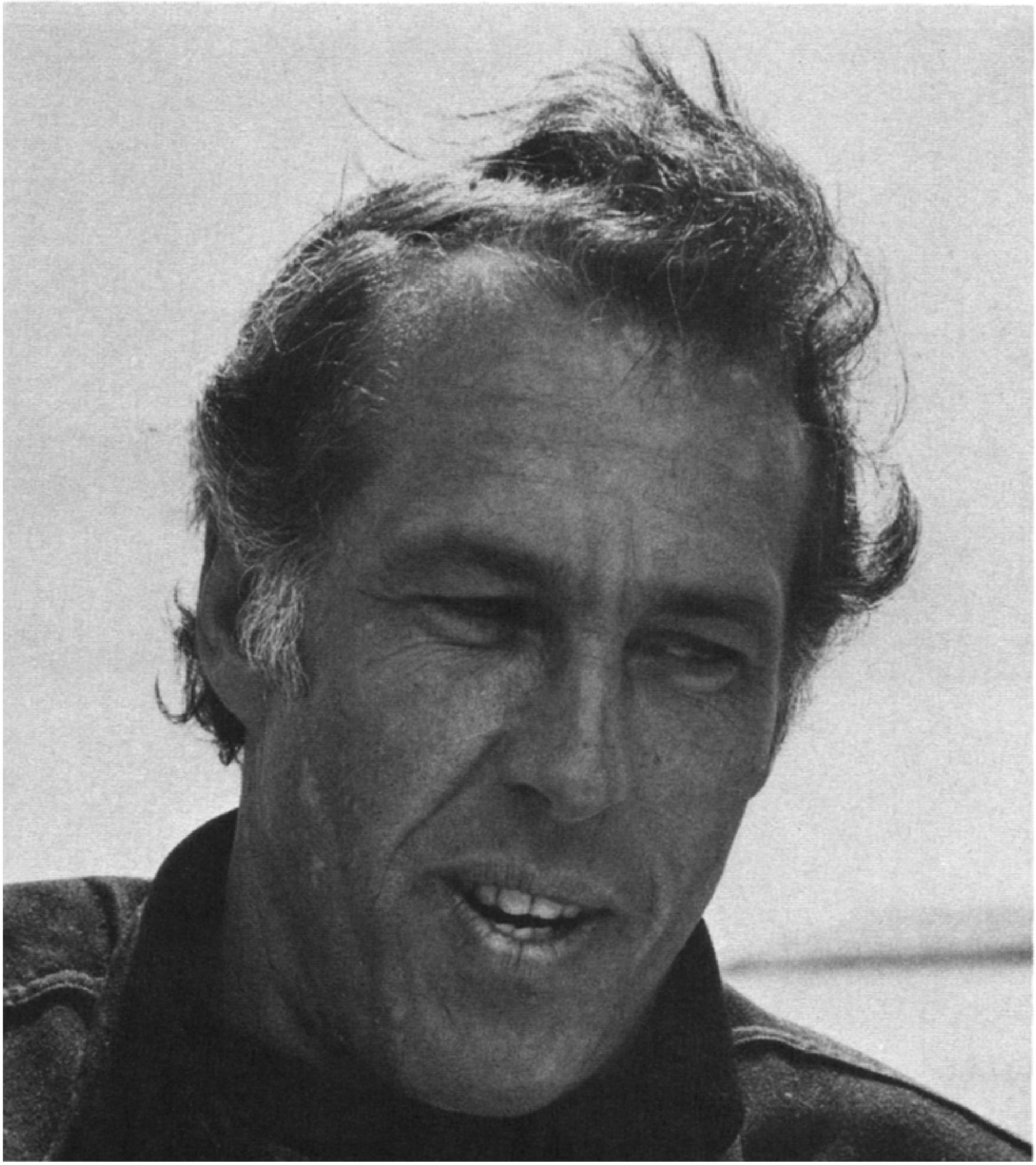
I suspect that it is Bob's respect for and openness to all ideas and all people which makes his life seem to work so smoothly. And he's a winner, of course, because that's what he decided to be.

6.6.5 Brian McCarthy

Presents A Day on the Bay

After a month on the road interviewing wheelers every day, I was tired of work, tired of extracting histories and wisdom from people, maybe even tired of gimps. So when Brian invited two friends and me to go for a sail on San Francisco Bay, I was eager to spend a day playing. Brian, of course, is a para.

It was such a supremely normal day of sunny recreation that I include excerpts just to show that days like this are out there for whoever wants them. They don't have to happen on a sailboat. Just pick nice places, nice people, and loaf resolutely.



Did you sail before your accident? “Yeah, so this was something very easy to ease into after the accident. And sailing’s a pretty easy sport. I mean, if you and I can get the boat set up and go sailing, you know it can’t be too difficult.”

Tell me about the boat. “It’s a little 22-foot Santana sloop, weighs 3,000 pounds, fiberglass. A couple of sails, a mast, all kinds of strings. Usual garden-variety stuff.” Done any racing? “Oh, a little bit in the Bay. Maybe about 10, 12 races a year. Local races, nothing fancy.” Ever win? “Occasionally. When I have a good crew.”

Why do you use braces? “Mainly to keep from falling off the boat.” That makes sense. “You extend them so you don’t slide off when you’re heading downhill.” I can’t even see that you’ve got braces on. “They’re those new fiberglass ones. You can even change shoes. That’s not a big deal to most people, but it’s a big deal to us. You can change your shoes without taking your braces off."

Could I operate a sailboat like this without braces? "It'd be a lot easier with leg braces, it really would. Because when it gets windy, you have trouble hanging on. We can get out in the windy part and watch you hang on. That'll be the laugh of the day. Your arms get tired. It's much easier to let the braces do the work for you."

How'd you have your accident? "Rolled a jeep, June of 64. I was 26." I thought you were a stockbroker then. How do you roll a jeep in the stock market? "I *was* a stockbroker. It was the army. It was that two-week summer training thing, you know, that we all had to do in those days. We hadn't thought about going to Canada yet, so went to summer camp instead."

Then you became a CPA? "I was in the stock market for a couple of years before my accident and about eight years after. Then I went back to school for a couple of years, which was really fun, getting back in touch with the kids again and just taking it easy for awhile." How's business? "Right now, it's very small. That's why we're sailing on Friday in the middle of the tax season. It'll grow. (Becomes tour guide.) This is historic Port Richmond now. This is serious stuff. We're gonna come about. (Comes about.) How's that? Look like the America's Cup, huh? We didn't even hit anything. You want to steer? (Moves into the cockpit, stands comfortably on bunks.) Don't bump into that piling over there, or any of the large land masses around."

At the end of the day, Brian took the helm and expertly returned us to the dock. His slip was easy to spot because of the two wheelchairs glinting in the afternoon sun. Nobody had missed them. Wheelchairs *are* the hot tip for most SCI's, but it's nice to leave them behind now and then. You don't need a chair to loaf.

6.6.6 Mary Wilson

“Recreation typifies fun, and that’s the bottom line in all this anyway. I mean, we can get as therapeutic as we want, but if you can’t have fun, what good’s your life going to be? You have to be able to feel that kind of happiness again.”

Mary is a raven-haired beauty, appears indecently healthy and looks as if happiness is a large part of her life. At lunch in a Sausalito restaurant, she interacts with others with a nice sense of authority. She projects herself with such confidence that no gimp/AB interface exists. What I guess that means is that she has a lot of poise.

Now we’re back in her nearby apartment, which is a cathouse (well, there are a lot of cats around), talking about recreation and SCI. Mary insists that she’s not a recreational therapist. Her schooling is in marketing. So she’s a Recreationalist or Therapeutic Activities Leader or whatever you choose to call her.

Mary got into whatever it is she does, of course, by breaking her back. “I made the mistake of falling out of a car. It was stupid, but you live ’n learn!” L1,2. 1973. Twenty-three years old. Rehab at Kaiser, in Vallejo.

She found an apartment, totally unsuitable, and then took an interviewing job in the financial district of San Francisco. “I spent my entire salary on taxicabs, going downtown, but it was good. It was maybe the turning point in my rehabilitation. It saved me, being busy.” The job convinced her that activity was the key to her survival. Her world tended to stop when her activities stopped.

A year after her accident, it was time for a hospital re-evaluation. “I was king of the mountain. Here I am, a veteran crip. It really gave me a whole different sense of myself. I felt extremely useful and valuable, that my experience was worth something.” She was offered a job as an aide to the recreational therapy specialist, took it, and trained and worked for six months as a Recreational Whatchamacallit. At that point, an administrative problem closed down the rehab center, and she was out on the streets again. She turned to *The Berkeley CIL*.

At CIL: “I was overwhelmed initially. My focus up til then had been new SCI’s, and I pretty much thought that all people in wheelchairs were of that nature. And to see all these active, integrated quads —I was really humbled. I almost felt guilty being a new para. But I went out and bought a whole bunch of flannel shirts and dug out all my old jeans, and before I knew it, I was there.”

Since I’d just visited the Berkeley CIL, I wanted to know what Mary thought of it: “I have a lot of belief in what a group organization can accomplish, and what they, in particular, have accomplished. Legislatively, they’ve done wonders for us. As a role model, they’ve done wonders. If you’re looking at it from the outside, it’s great, and that’s a good purpose they’re serving. When you’re living within those confines, it’s a different story. I see it as a haven, a sheltered environment and a real hideout. I know a number of people who cannot survive outside of that. Then you’re losing what, hopefully, you were trying to accomplish.”

Mary put her flannel shirts aside, finally, and went back to work as a Whatchamacallit, this time at the Ralph K. Davies Medical Center in San Francisco. Whatever her job description was, it involved recreation.

She feels that sports and recreation are far and away the easiest way to educate the public on disability. “People have a tendency to believe that life pretty much stops upon injury. Things do go on, and seeing people out and active and *smiling*, no less, is always an education to the average person. So we’re using that as a way of getting our community accessible and educated, our programs funded. It’s serving many purposes that have not a whole lot to do with sports.”

And the sports themselves? “I think the sports circuit itself is great because it helps build self-esteem, because you’re developing your physical powers and your coordination and mobility. You’re used to being looked at. You’re under focus. You’re traveling, you’re meeting lots of people —it has a lot of really healthy side effects. I mean, I’ve never seen such a smorgasbord of healthy people in my life as I have at the National Wheelchair Games.

“With the young people that are on our team, it’s doing amazing things. Positive, healthy things. When you’re growing up, sports play a big part of your development, so it’s giving them an opportunity to develop in similar areas. For the older people on our team, it helps keep them down to earth. They don’t get too consumed in their professions. It keeps you rounded.”

How about the much older people? “I think it keeps them from getting locked into little groups where they become isolated. It keeps them in the flow of things. I don’t see any kind of age discrimination going on amongst the competitors.”

I wanted to know what high SCI’s can do for recreation: “Not very much until they come down. Oh, you mean high *level* injuries. One fellow, who got involved in the program last year, is a C4 quad. He does have some arm movement — enough to push a chair — which is the criterion for getting into wheelchair sports competitively. After his first season of running with us, he was incredibly enlightened to the fact that he had some physical powers, that somebody gave him some involvement on a physical level. Prior to that, I think everybody had been saying, Well, John, Go to school. Get a degree. Develop your mental powers. He felt that that was his only option for involvement in society.” In this case, sports got him into traveling so much, worldwide, that he is now going to a travel agents’ school so that he can open a travel agency. In Thailand.

It’s not all sports. Mary speaks of a Cl quad on a respirator, an artist before his injury. He got back into painting, using a mouthstick, and is now opening a cafe/coffee house/ gallery to showcase his work. “That’s pretty amazing, a Cl quad not just integrating into the community but running his own business. And his big thing is mingling, socializing, showing people his art work; and that’s an active stance.”

For most new high level injuries, Mary feels that recreation is partly a matter of getting out in the community a lot, regaining confidence in the world, going to theatres, parks and restaurants. “Anybody can develop game skills, or the low key diversionary activities, but it takes exposure and a little bit of technique to learn how to handle yourself out on the streets again.”

While Mary's getting new injuries back on the streets, she's getting herself out on the Marin County jogging paths, working on long distance pushing. She likes the reactions she gets from passersby: "They're positive, friendly, accepting reactions. Everybody's sort of delighted that we all have some sort of similar mobility now, whether it's on a skateboard or roller skates or a bicycle. All different forms of wheels out there. They all want to know, Why are the wheels tilted, Why is the chair this or that? That's neat! Let's see you do a wheelie."

Other plans: Mary wants to model and/or act in commercials and films. She sees no reason why someone in a wheelchair couldn't present the product just as effectively as a normie, and she'd like to be the one to break that ice. I tried to call her recently, and found that she's no longer at Ralph K. Davies. Maybe she's out having a Pepsi Day. Maybe she's racing through airports, blowing Pepsodent kisses, squeezing the Charmin, or just having fun.

Parting shot: "Sometimes it's hard to have fun or sometimes it's hard to laugh after you go through some of the experiences that we have all shared. But there are ways of finding that kind of joy and happiness again. It keeps coming to mind, that old song, *I Ain't Never Had Too Much Fun*. And that's real true."

6.7 Recreation

6.7.1 Generalizations

Recreation, for a para of any level, is a cinch. Choose from any of the sports and activities listed below and add a dozen of your own. Recreation for a quad is more limited, but still very available. If you are a high injury, and if some of these activities seem like lousy substitutes for what you once could do, you should know this: As you and your injury mellow through a little time, you'll find that you don't think much about walking. Nor will you think wistfully about skiing or diving or whatever you used to do. You'll start to think, with interest and pleasure, about the things you can do now. Your body, at least as much as your mind, learns eventually that what *was* has very little relevance to what *is*. What does exist, recreationally, is a host of possibilities.

6.7.2 Specifics

There are all the obvious diversionary activities: reading, knitting, cards, air hockey and shuffleboard are five of hundreds. Hobbies: stamp collecting, photography (controls for quads have been contrived), electronics, CB and ham radio (there's a blow device so quads can send morse code). Social: sex, dancing, (disco, square or any other kind).

The arts: writing, drama, music, cinema, painting (there are now orthodontically fitted mouthpieces for holding brushes). There's something rec departments call Contemporary Activities: I think it means frisbee and thumb wrestling. Getting out: gardening, your car, all terrain vehicles, dune buggies, trikes, motorcycles (with or without a sidecar which accommodates the chair and rider and allows him to drive). Hunting and fishing (there are anti-gravity devices to facilitate holding a gun or rod, and laws exist which allow you to shoot from a vehicle). Travel. Flying and soaring (hand controls are available).

Indoor sports: Bowling (quads can use a suitcase handle release or an aiming device), darts. Pool and billiards. Martial arts. Fencing. Table tennis. Weight lifting. Basketball— when played well, wheelchair basketball beats the AB'd kind.

Outdoor sports: Croquet. Wind surfing. Sailing. Swimming (all strokes and all distances). Riding horses (saddles have been adapted). Pulks (sleds which can be controlled on ski slopes or self-propelled cross country). Tennis. Volleyball. Football—really! Cross Country. Kayaking (a low para can roll, i.e., right himself after a capsize, but you don't *have* to be able to roll). Rafting. Canoeing. Track and field events— dashes and pushes, from 40 meters to 26-mile marathons, shot, discus, javelin. Archery — excellent for quads.

If you want recreation, it doesn't matter how you get it. Take it as it comes. When you're ready for some fun, it's there waiting for you. And if you're down on wheelchair recreation, please read the next section on the wheelchair games. Or read the *Susan Schapiro*, *West Brownlow*, *Mary Wilson*, *Cliff Crase*, *Syd Jacobs*, and *Mark Johnson* profiles.

And then again, in SCI as in the rest of life, a lot of us get our kicks and rewards entirely from our jobs and relationships. You don't have to be a jock or a chess master. But if you want to be, you can.

6.7.3 Wheelchair Games

May, 1979. The Rocky Mountain Regional Wheelchair Games. I knew ahead of time that I'd hate the whole show, because I knew that the Games require gimps to do badly, and imitatively, what they could once do well. Why do something that so blatantly displays our limited function? Our courageous smiles? Besides, I don't like competition. To hell with the team, show me the singular beauty of perfect execution. I came, in short, to scoff.

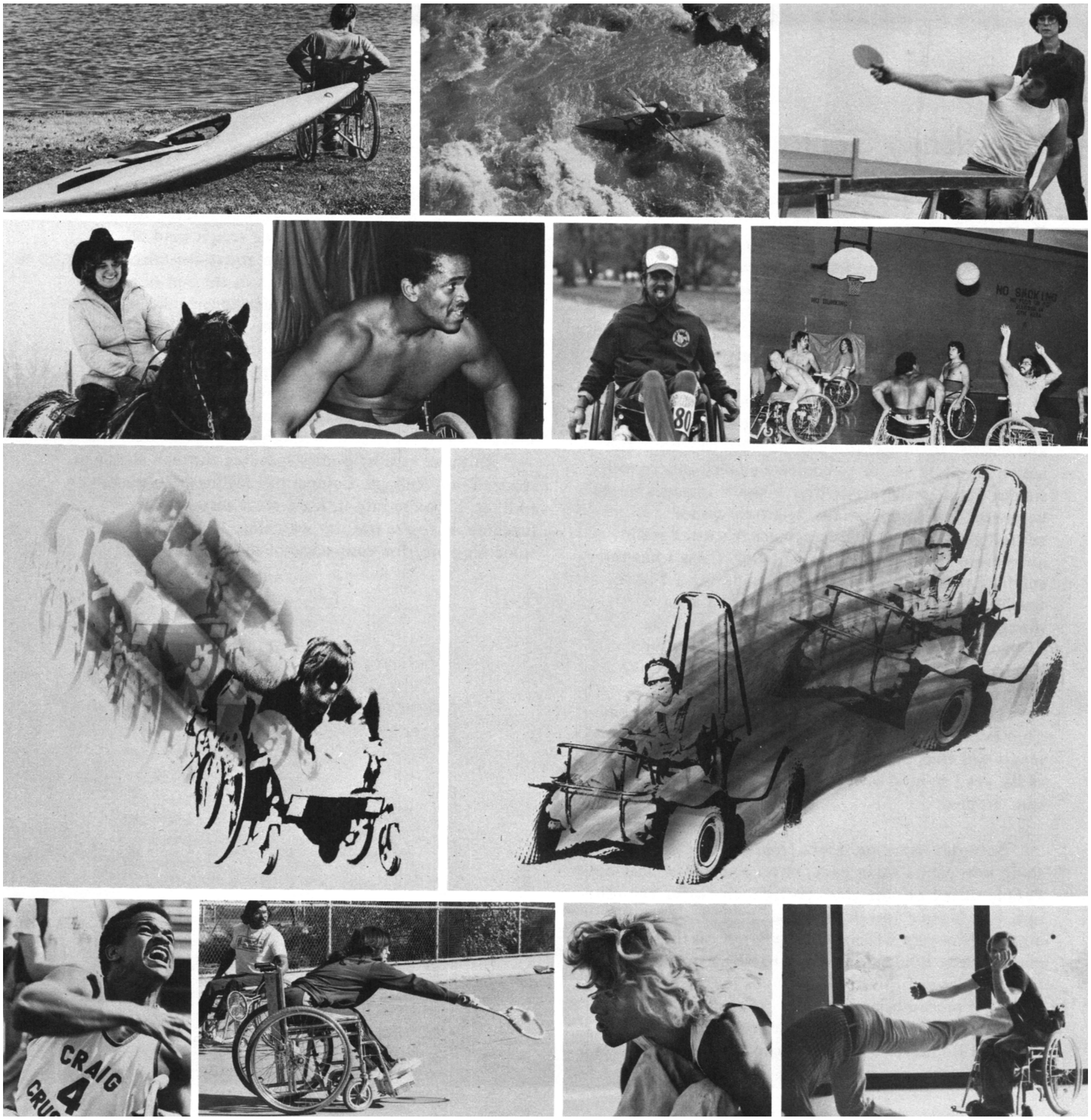
Classification: This is the first event and is dominated by doctors. They examine the contestants and classify them according to physical function. The idea is to allow people to compete against others with similar abilities and disabilities. Class V includes single below-the-knee amputations, relatively minor neurological damage and hangnails. V's often walk away from their chairs after the event. Class I has three subdivisions, but is generally for quads. As a T12, I would be a IV. Now one of the reasons I always thought golf was a silly game was because of the handicap system. Here it is for real. What's your handicap? Uh, sir, I can't seem to walk. OK, you're a III.

Things picked up when the events started for real. That evening, it was table tennis and slalom. The table tennis was fine, and the slalom showed me some real skills, yet I refused to relinquish my right to wallow in sour grapes.

Saturday morning. Light chairs, long chairs, chairs slung low, chairs slung back, sweet swung-low chariots. People sitting on the grass giving their chairs fine tuneups. How's your anti-flutter? Axle positions by the dozens. Nine-clip wheels. One hundred psi tires. Low mass casters. Spiders and small handrim overdrive. Camber plates. In this crowd, quads included, my chair and I are precambrian.

Realization: These people are real athletes. Another: Bodies in wheelchairs can be beautiful. Lines of perfection on Mikel Strole's face as she psyches herself for the discus. A quad gives everything to complete his race, and I know I've seen a kind of beauty I don't find elsewhere. An above-the-knee double amputee passes a low para at the end of a 1,500-meter push, and it's done with such spectacular strategy and grace that I'm dewy-eyed. West Brownlow, classified IC, joyfully fills in on relays for a missing II or III because he really wants to run. It's beautiful. Our lives are partially run by the need to see things done very well or very resolutely. There's no difference. We're all suckers for the hero in one another.

All those healthy bodies speeding through classified space. Team feelings. Competitive feelings. *Normalcy* feelings. If you're into it, it's a great socialization machine. If you're not, try watching. It might do something nice for your sense of self-image.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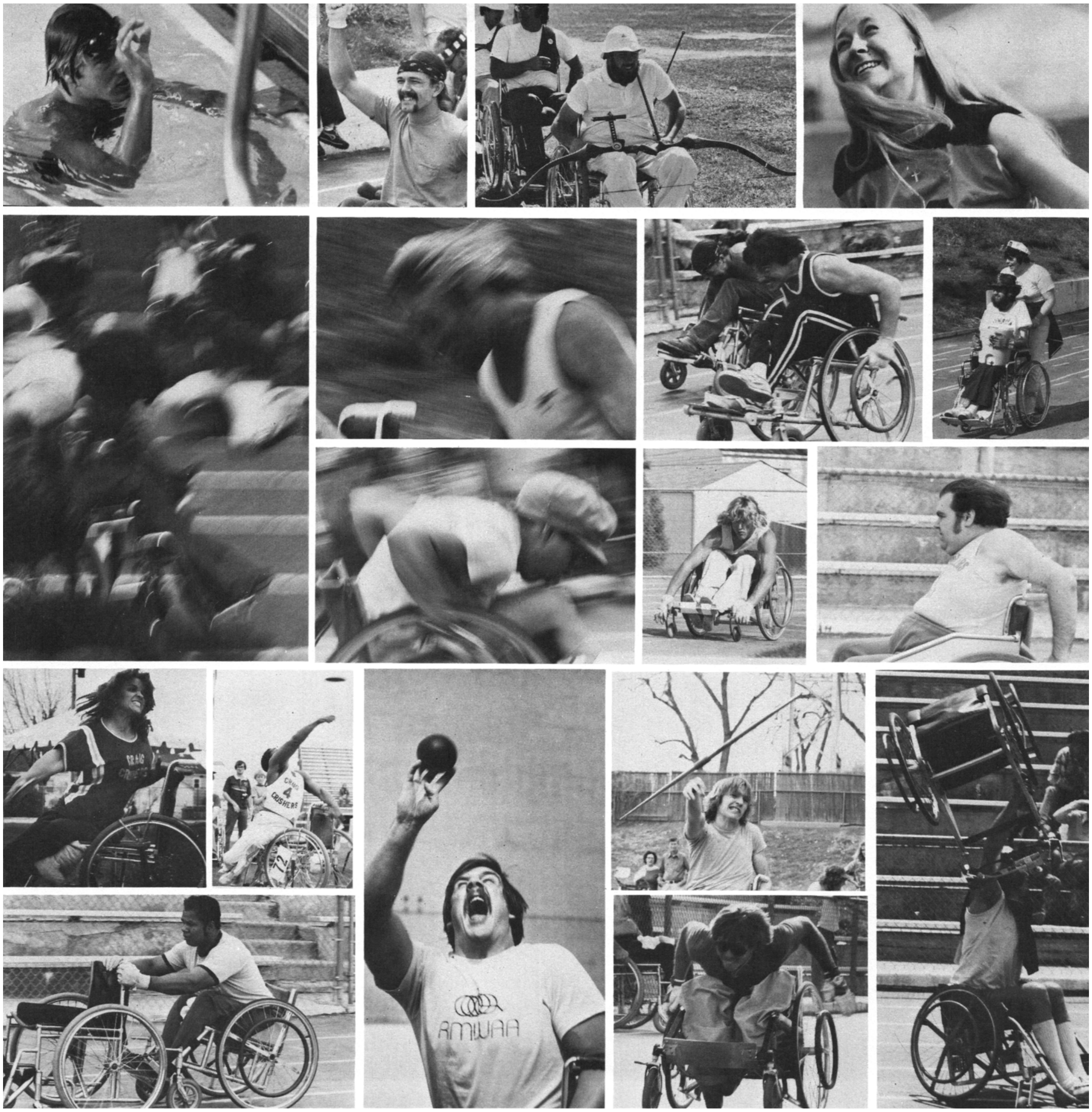


6.8 Lives IV

6.8.1 West Brownlow

For years, some friends and I had a good deal at a swimming pool at the University of Colorado. It was called a kayaking course for the disabled. I was the token gimp, and my many “instructors” and I got to use the pool to run gates or practice Eskimo rolls or just horse around.

Then one day, this guy with a *real* fast wheelchair —you know, no brakes, no armrests, cambered wheels, nine-position axle, tiny casters, damped forks, spoilers —well this guy showed up with a borrowed boat, put a piece of packing foam in the bottom of the cockpit, braced his back against what looked like the side of an orange crate, and announced that he was ready to learn to kayak. His injury looked high to me, perhaps T2, perhaps too high for a sport which demands so much of the upper body. West didn't know or care. Now, he's a pretty fair kayaker. And he's not T2. He's C7,8.

Here's West, about four days away from wheelchair or van, on the San Juan River. He got there by kayak.

After two years at the University of Vermont and two years of active duty in the Navy, what West wanted to do was ski. He became a Racer Service Representative for a prestigious ski manufacturer, did some coaching on the side, and, in 1973, broke his neck skiing at Waterville Valley, New Hampshire. He was 27.

He spent 10 days in Concord, New Hampshire, where he feels he got good care. They did a laminectomy, and he credits the resultant relief of pressure for turning what is orthopedically a C5,6,7 fracture into C7,8 function. He has good hands, good arms and minor dysfunction in his wrists. His doctor in Concord knew of Craig, and did a masterful job of convincing both West and his insurance company that that was the place to be.

For West, it was. "Immediately after my accident, I entered wheelchair sports. Then in the winter, I was exposed to basketball and I started doing that."

West has become a wheelchair jock. In the world of wheelchair sports, he is a prime contender in whatever he enters.

"Wheelchair sports, for me, have been a Godsend. Sports are a big part of my life, competitive and recreational. Track and field events, basketball, archery, swimming, tennis, kayaking, scuba diving, sailing, flying, soaring … as the years progress, I've been searching out sports which don't require that everyone be in a chair, because we live in an integrated world and I enjoy it that way."

One of his more integrated efforts took place last April when West, *Syd Jacobs*, *Hank Atkinson* and I joined several AB's for a five day trip down the San Juan River in Utah. The river was unseasonably high, the water viciously cold and the whole prospect of extended camping, 80 miles of seemingly treacherous rapids, and the logistics of coordinating four bowel programs caused visible apprehension amongst the new boaters. West: "I was, and this is an understatement, terrified." The trip went well, and both West and Hank have since repeated the trip. Without the terror.

On the first trip, when West was presented with his wheelchair after a few days without it, he did wheelies and spins for about five minutes, just like a happy puppy rolling in sand. He *likes* his wheelchair. He was *glad* to see it. For me, the greatest part of a river trip is that I get to leave my chair behind, sometimes for weeks at a time. If I could physically do it, I'd kick mine to death at least once a day just on general principles. Not West: "This (chair) is a part of my body. I feel very friendly towards my chair. I like to keep it running at least as well as a Swiss watch. If it's not running good, it feels bad. I wouldn't want to be walking around with a limp if I could fix it just like *that*, and you can do that to your chair."

What about modifications to the chair for sports?

“I would compare them to different types of shoes or boots —track shoes, hiking boots, running shoes, whatever. You have to set up your chair for the event. For basketball, marathons, everyday use, you set it up differently. It’s a revolution, and I’m glad it happened because it has opened all kinds of doors for what you can do with your chair.”

Basics:

- Movable axles, normally to get the center of gravity forward. This shortens the wheelbase, so the chair pivots faster. Long distance pushers want to lengthen their wheelbase.
- Cambered wheels. The wheels are wider apart at the ground than they are at the top. This provides lateral stability and a built-in tendency to turn.
- Various casters. Small, hard rubber casters for basketball and other hard surfaces, larger pneumatics for fast outdoor rolling on all fours.
- A Pandora’s Box of adjustments, including seat and back height, sealed bearings, instantly removable wheels, small diameter handrims, spiders, no-flutter caster forks and dozens more.

One of West’s modifications is for the twenty-six-plus mile marathon. He’s run several, including the Boston Marathon (he won his class, pushing in the rain), and uses a chair with an extended wheelbase and steering handles on the casters. For the downhill segments, he wears thick leather pads on the insides of his elbows. These are his brakes, since his hands are down stabilizing the casters. We filmed him on the Peak to Peak Marathon in Colorado, which wanders between 7,000 to 9,500 feet in elevation. “It *is* hard work. There’s a *lot* of uphill on this course, a lot more than I had realized. Sometimes you don’t even coast with each push. A big thing about the uphills is that it has removed every slightest ounce of guilt that I ever felt in going past people (AB’s) on the downhill. I used to feel guilty about that.”

This course has a seven mile downhill stretch. “The policeman told us afterward that he couldn’t keep up with us after about 45 miles per hour on the curves. The first time, I was terrified. After you’ve learned that your equipment can handle the conditions, you can really get flying. It reminds me of downhill skiing, in your picking of the line, and the speed, and the position— you’re in a tuck and your face is about a foot and a half above the pavement. No, I’ve never crashed. (Knocks on table.) I have gotten air.”

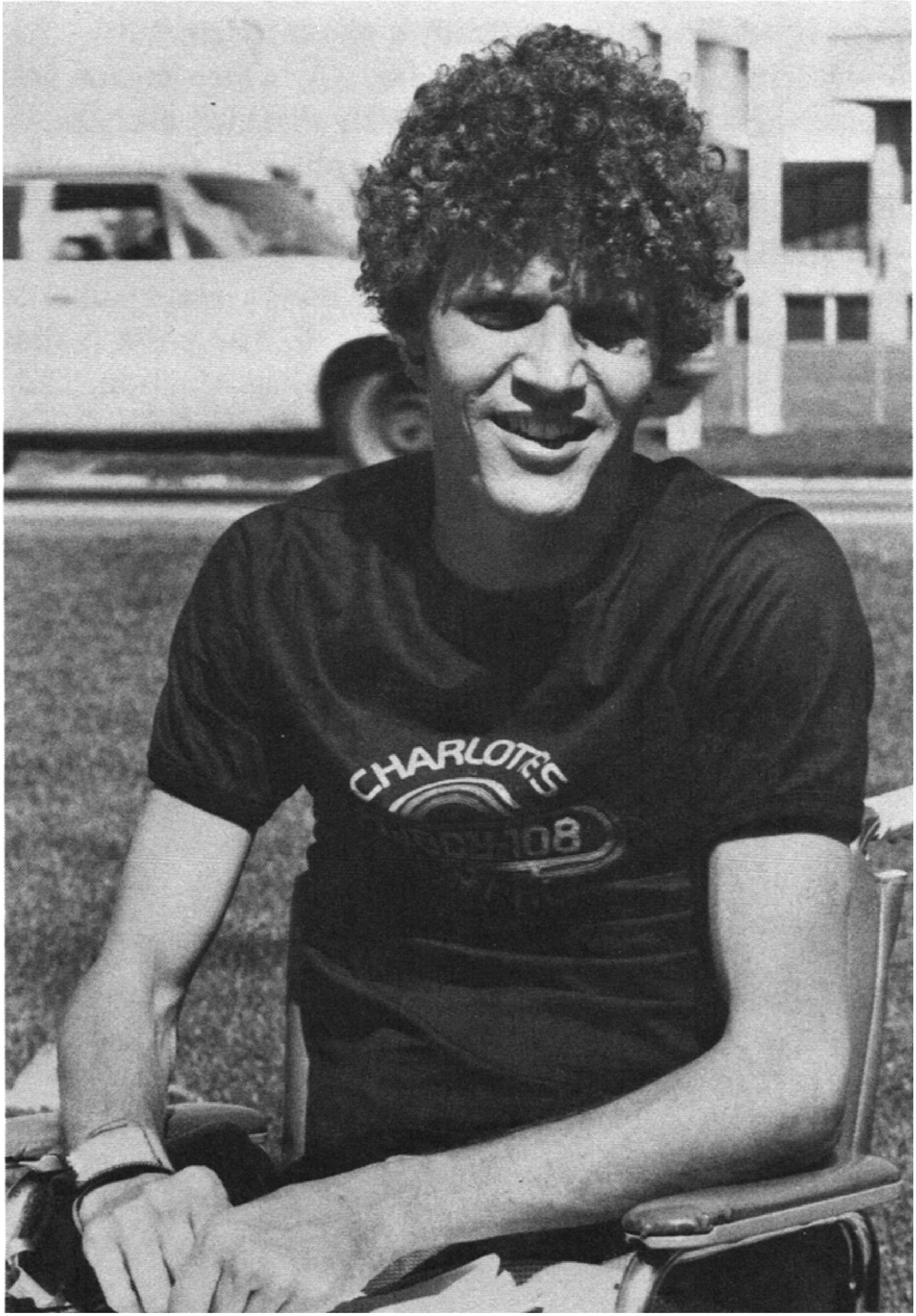
Actually, West isn't all hardcore: "One marathon, some kids were doing dressage alongside the course. I stopped for a couple of minutes to watch, because I love horses and love kids too. I figured, what's two minutes out of three or four hours? You might not have the opportunity again. And taking advantage of opportunities as they present themselves is very important to me. There's not always another chance."

What else does he do? "Despite appearances, I do a little bit of work in investments and real estate." He gives demonstrations at school assemblies, exposing kids to wheelchair sports. He is extremely sensitive to AB's who automatically think wheelers are deranged or sick, and wants to present a positive image. "I feel it is my responsibility to educate the public. I feel that everyone in a chair is an ambassador."

Parting shot: "People seem to feel they always have to discuss their problems, disability, this kind of thing. And life is going on around us. (He gestures toward a wooded meadow.) You know, there's thistles growing here, there's trees, there's fun things to do. I mean, *things are happening*. Grass is growing. And we're all living life."

6.8.2 Mark Johnson

I first saw Mark at the 1979 NSCIF Convention. He was speaking from the floor, so all I could see was a frizzy head of hair and all I could hear was the most down home North Carolina accent imaginable. That's what I need for this film, I thought, I need a good ol' country boy. So I tracked him down and asked if he'd loan me his accent. He would, he did, and he's about as down home as the President.


CHARLOTTE'S
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At the end of his sophomore year in college, Mark went diving instead of studying for his English exam. He distinguished himself, in the rarified world of diving injuries, by breaking his neck without hitting anything harder than water. He ran down the face of a rock quarry and did a shallow surface dive: "I just kind of coasted through the water and noticed I couldn't move. Apparently I didn't hit anything." C5,6. 1971. 19 years old.

He spent two months in general hospitalization, three months at the Charlotte Rehabilitation Hospital, five months with his family and returned to school. DVR paid his, books, tuition and transportation. Later, they financed his van lift and controls so he'd be able to transport himself to work independently. Considering how frustrated others have been by DVR, I wanted to know how Mark had been so lucky.

"What I found out is how to play the VR game. And the VR game was to smile, be happy and lay down your plans to 'em. I'd just say, this is what I want to do. Here. Because by then, I started seeing it as a service I was entitled to. Heck, go out and break your neck, why not use it?"

Perhaps life does begin with spinal cord injury.

"That's a good concept, really. It helped me realize that there were certain priorities in life. It's a shame you have to be knocked down and kicked a few times to realize that, but I used to take stuff for granted. You know, I wanted to be taller, bigger, faster, stronger, smarter — you want those things, and all of a sudden you realize *I'd like to be able to tie my shoes. I'd like to be able to clean my own fingernails*. That kind of stuff starts to take priority."

How about relationships with other people?

Before his accident: "I was always shy. I had trouble initiating relationships. I had more sisters than I knew what to do with."

After his accident: "I'd say, Is a person just interested in me because I'm this horrible handicapped person? Are they interested in having more than just a verbal relationship? And so I got to playing games with myself. I'd say, Oh, they wouldn't be interested in me physically. Ultimately I said, What's the worst thing that can happen to you, Mark? Rejection, or not even trying to get your needs met?

"It took close to five years to finally realize that I wanted to get my needs met. I verbalized a lot of things: You know I'm paralyzed, you know I don't have much sensation, or if you don't know this, I'm gonna tell you. And I'm gonna show you. And I'm gonna reach out and touch you and I'm gonna hold you because that's something I need to do and I want to do. And it's worked."

Mark came away from school with a bachelor's in psychology, a master's in education, guidance and counseling, and a lot more confidence. He applied for a number of jobs and was offered several.

"Then the hospital (in Charlotte) said Listen, we need somebody to do community stuff. And I asked, Do you see me doing this? Do you see me being able to do this? And they kept answering Yes. And what the position entailed was individual, group and family counseling, in-service education, staff consultation, community relations, goin' to talk to groups about attitudes, doin' all that kind of stuff, and I said, Hey, this is unreal. So they called me up, said Do you want the position? I said Yes. They said Do you want to know how much you'll make? I said No, it doesn't make any difference to me. I'll take it. So I took it.

"The last three years, everything I've done, it just seemed like the perfect time to do it. Everything fell into place. I woke up in the morning, went and did it, and I said, Whoa, that worked out alright. Let's try this. And then I just kept doin it."

Mark is aware of the opportunity and the need to be a role model, both for the disabled and the able bodied. An exemplary gimp. A quadriplegic ombudsman: "I'd send people on errands back in the beginning years. Hey listen, there's a curb there and I'm not gonna be able to get up it. Well now, if it's a flight of steps and there's something in that building I need or want, I'll go there and approach the general public and say, Hey listen, can you assist me up through here? The visibility of it all— people say How did you get up here, and I say, I had about four people carry me up this flight of steps. It automatically sinks into 'em."

Recreation: Mark is classified IA, which means he's competing against the most severely disabled athletes, and he does it in the dash, slalom, obstacle course, shot, discus and javelin. He likes competing against people with similar motor function because it creates a fair field. He swims, plays table tennis, bowls, plays billiards and practices with the basketball team. The point is that recreation brings him a lot of personal satisfaction, and the *way* in which he recreates is unimportant.

Hot tip: "You gotta learn to laugh, you gotta learn to verbalize and you gotta be patient. Because it's goin' to take time, definitely goin' to take time. But it's all worth it."

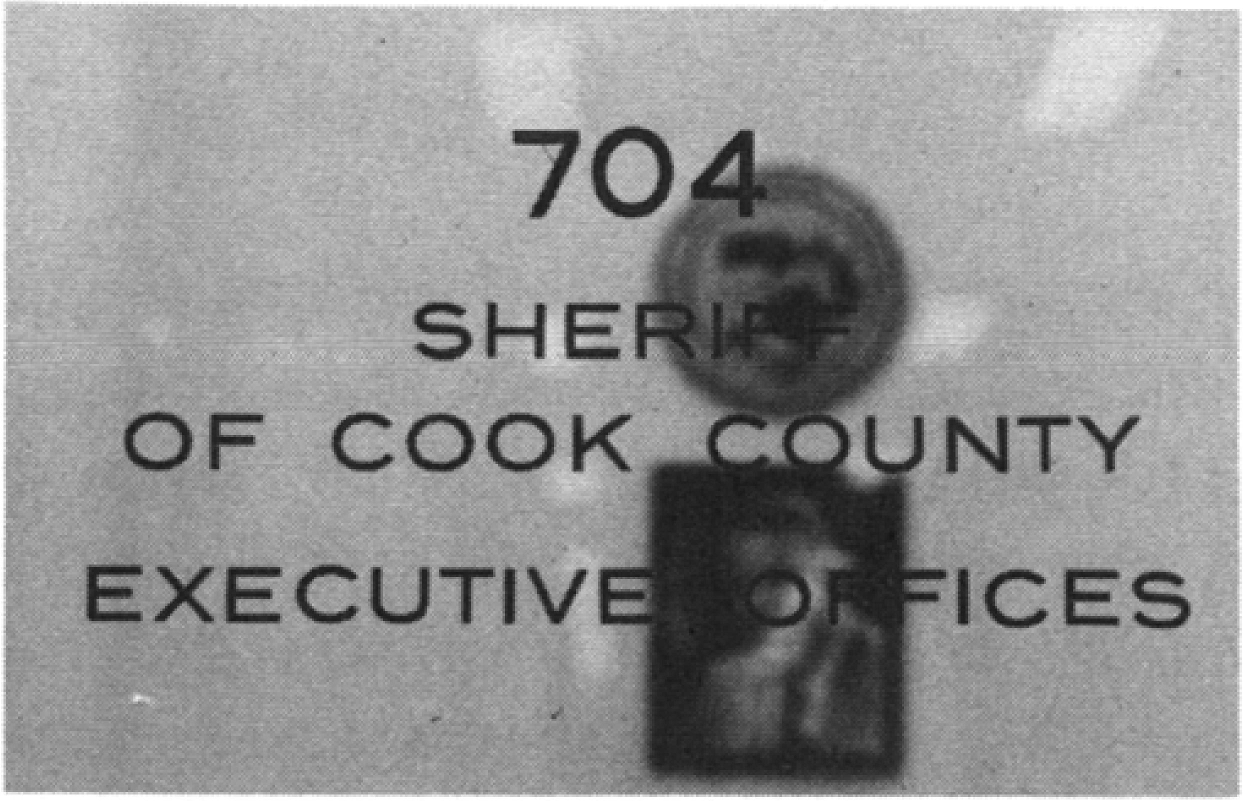
How long did it take you?

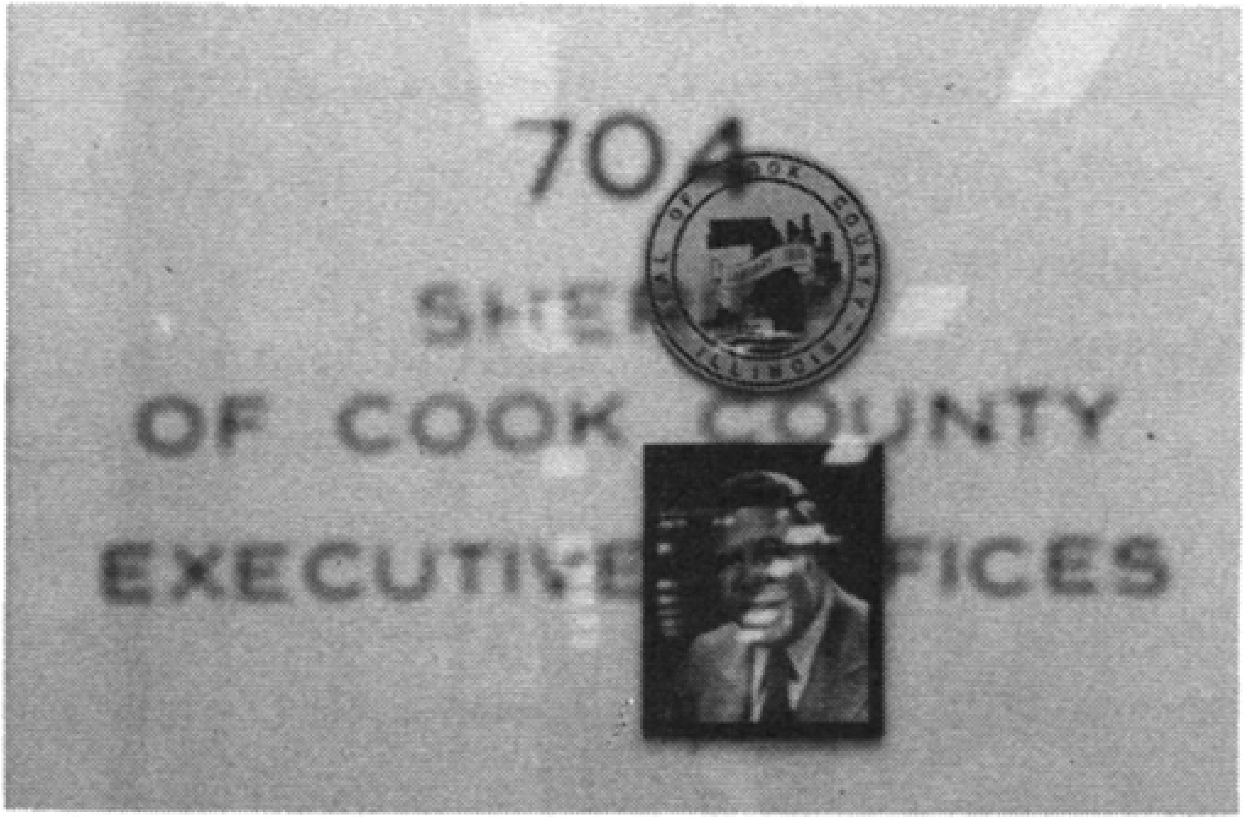
"It's still goin', and it's been eight years."

6.8.3 Richard J. Elrod

Cook County, Illinois, is enormous. It has 920 square miles, including Chicago, and five and a half million people.

In 1970, and again in 1974 and 1978, the people of Cook County elected Richard J. Elrod as their Sheriff. He is, and was before his first elective term, a C4,5,6 quadriparetic.





I was nervous about this interview from the start. I knew that Sheriff Elrod had been injured in a civil rights demonstration in 1969, kicked by a hippie or a yippie in fact, so I thought that he might spot my rather obvious sixties sensibilities and hold them against me. When I found out that the interview would take place in the Richard J. Daley Building, I thought he might simply hold me forever. When I was told to drive into a basement security area and meet a deputy for escort, I very nearly bolted. As I wheeled past the guard at the elevator, past the guard at the outer door, past four secretaries lined up one after another, past a plainclothesman at the inner door (who turned out to be the Sheriff's son), I was truly miserable. Having penetrated to the heart of the beast, I wanted badly to go home.

The first nice surprise was being admitted immediately. I'd always thought that making people wait was an accepted sign of professionalism in government. The second nice surprise was that very highly placed cops can be friendly, warm and responsive. Sheriff Elrod quickly confessed that he had no idea who we were or what we wanted, offered to help us in any way he could and proceeded to give generously of his time and talents.

It turns out that, in the sixties, Sheriff Elrod went to a lot more demonstrations than I did. As Chief City Prosecutor and Legal Advisor to the Chicago Police Department, he went to them all. When the Weathermen triggered the Days of Rage in 1969, he was on the job as usual. He tried to stop a fleeing man and ended up with a crushed C5 vertebra.

After five months at a general hospital and seven months in the Rehabilitation Institute of Chicago, he regained useful but incomplete function of all four limbs. He seldom uses a wheelchair, doesn't use braces or splints and is ambulatory with one cane and one modified Canadian crutch. As he sits behind his desk in an upholstered swivel chair, the only clues to his disability are a crutch on the floor and somewhat deliberate hand motions. Mostly, he looks like any executive anywhere.

At the time of his accident, he was already slated to run for the Sheriff's office. What's remarkable is that, in spite of 10 months of hospitalization, he stayed on course. He campaigned from the hospital and won the Democratic primary nomination. As election politics warmed up, he put in full days of therapy at RIC, then spoke almost every night at a dinner, fraternal club or other gathering. It was part of his rehabilitation process. He first won election as Sheriff in November, 1970.

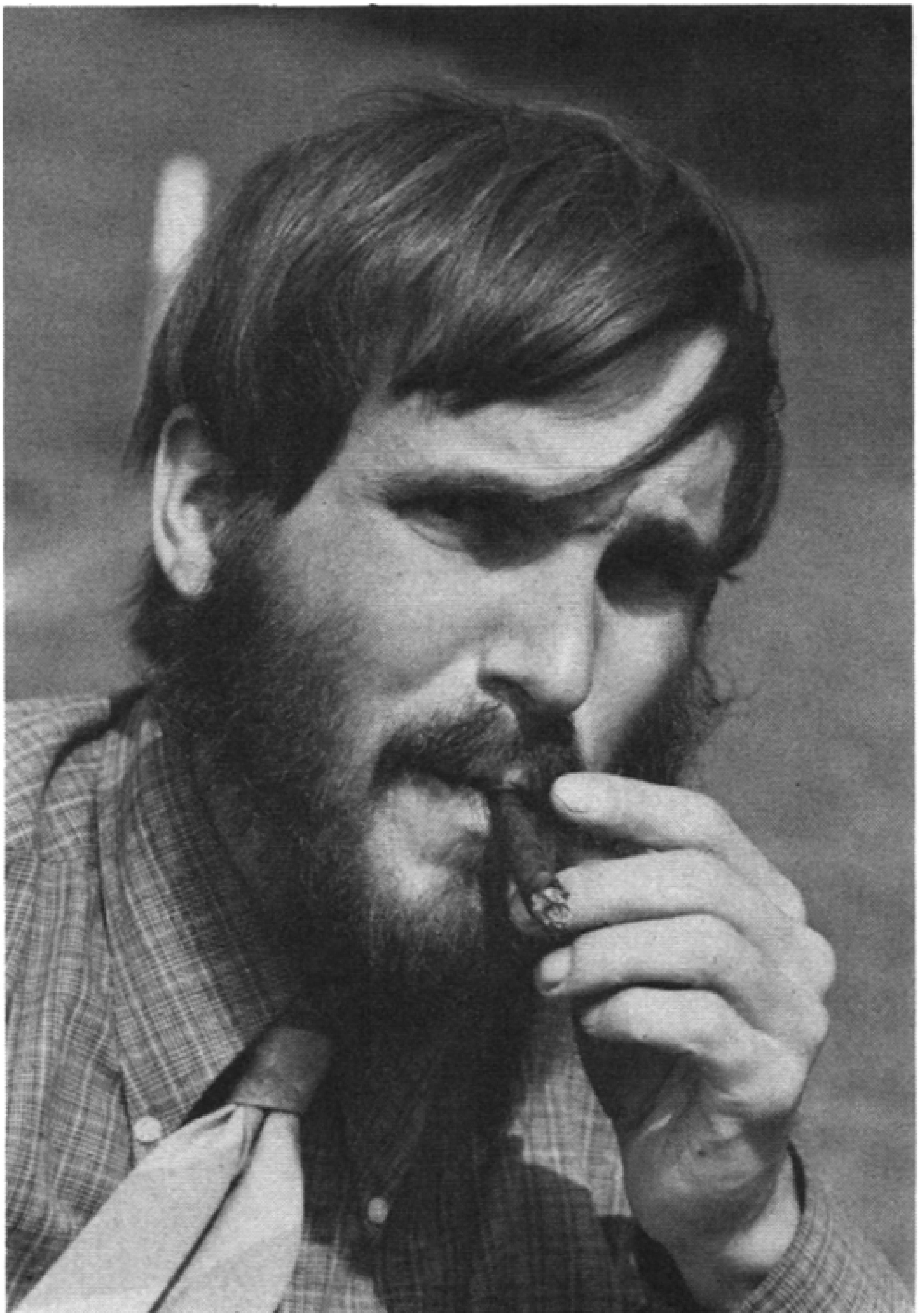
In addition to staggering law enforcement responsibilities, the Sheriff's office employs 4,000 people and dispenses an annual budget of about seventy million dollars. Has his injury limited his effectiveness?

"The Office of Sheriff is a very demanding one, but it's basically an administrative office. If you pick proper department heads and proper administrators, you can set the policy, you can see to it that you're operating within the parameters of your budget and you can go out and see the people as often as possible. I must make three or four speeches a week. It's a large county, and I believe that as much as I can be out, I am out.

"I spend 10 to 12 hours a day in the office, in addition to being out. I think that having had this injury, and being handicapped, actually helps me run a better office because I can put in more time. I don't have the diversionary aspect of wanting to go out and play golf, or handball, or touch football or skiing. This is my job and this is what I've devoted my time to for the last 10 years."

6.8.4 John Breasted

He's a journalist, and looks the part. Chinos, checkered shirt, loosely knotted striped tie, pockets full of pens and pads, and a constant conflict over whether to smoke a pipe or a cigar, neither one of which stays lit.



When he was 19, in 1967, John had a skiing accident. He collided with a tree, the tree won, and he is now a T8,9 para living in Hartford, Connecticut. Somehow, by coincidence, by plain bad luck, by professional malfeasance, by his own indulgence and that of others, by getting caught in institutions more oriented to sickness than to health, by a lot of lousy advice or by a combination of all or none of the above, John got pretty messed up after his accident. More, and for longer, than most of us.

He's fiercely intelligent, almost the proof that brains are a liability in this SCI business. Whatever happened to him is clearly not a result of a lack of moral fiber or determination, because he has met, face to face, the most fearsome demons that any of us encounters in life. He is brutally honest about his experience, not because he likes talking about it, but because he knows that a lot of others are just as depressed as he was. He has reviewed this profile and has agonized over authorizing its publication. His permission is a courageous and generous effort to help.

After six weeks of stabilization at a general hospital in Denver, he flew to New York to be closer to his family. "I was at (a New York rehabilitation center), initially, for nine months. Then I went back for three more months within a few weeks."

Complications?

"No, I was scared of the outside world. I had no physical reason to go back. The attending physician felt it was appropriate to take me back just as a kind of shelter."

Even before his first discharge: "I can remember valuing the protection of the hospital more and more as the date of discharge drew near. I learned afterward that there are a lot of people who went through the same thing. They were very afraid to leave. Some of them were scared out of their minds with it." And John's timing was off—he got hit hard by a broken love affair just before he left the hospital.

"One of the things that's most disturbing to males when they get hurt is the relationship with women — intimate love relationships, erotic relationships — and it certainly was to me. As a 19 year old who'd never had intercourse, it was very disturbing to wake up numb below the waist. I felt very cheated. And then to have the first woman that I slept with be someone I met after I was a paraplegic and then have her jilt me…"

He learned to drive, went to live with his sister in Manhattan and went part-time to Columbia. The University was inaccessible, the courses too technical for someone more in tune with his emotions than his intellect, and "It was too much to bite off, too abrupt a transition and scary as hell living in an apartment. Plus everything was so scary about Manhattan." And the experience with his first woman nagged a little too much. Hence the headlong flight back to the rehab center.

The center couldn't do very much. They're in the rehabilitation business there, and psychiatric care for the severely depressed is something else. John's doctor referred him to a psychiatrist "who runs this *crazy* operation in Pennsylvania. I spent seven months there, in residence in a house that my parents rented at great expense, and supposedly the shrink's supposed to come in and see you every day. And this is the way he, successfully I gather, several decades ago treated real far-out schizophrenic cases. Well, he's trying to apply it to just plain ol' depressed people like me. At that point, I was *so* depressed —after a while you're just willing to try anything and you kind of let people push you into things because you're trying to get other people to make decisions for you. That turned out to be disastrous."

The famous psychiatrist quickly delegated his duties to a junior psychologist, the place was a battlefield of petty jealousies and haggling, and life there was not serene. "I got increasingly desperate there. I attempted suicide. At that point, they didn't want anything further to do with me because they weren't equipped to handle overtly suicidal behavior. I mean, they just dumped me on my parents and my sister. They called up and said, You come down and get this kid. We can't handle him.

"I went through over a year of really severe depression after losing that girlfriend in November of '67, before I was able to function as a paraplegic in any kind of meaningful way in the outside world."

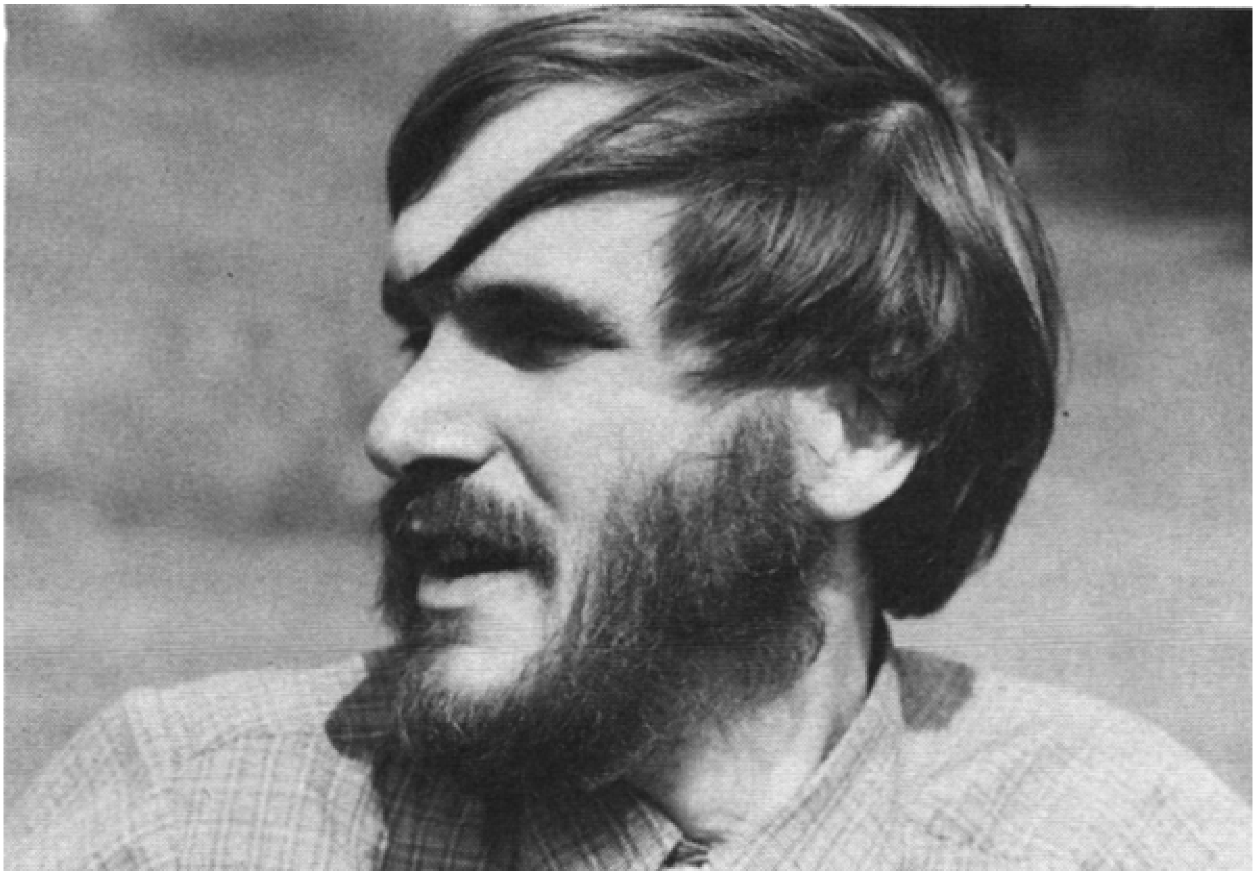
Was there a turning point?

"I would say it was another hospitalization. My parents didn't know what to do with me, and they called a neighbor of ours who's a registered nurse with her head screwed on right. And she said that they seemed to have a good psychiatric service at Yale-New Haven Hospital and why didn't they call them up? That was a good move. Yale-New Haven turned out to be a place that helped me out a lot, and I was able to pull out of my depression there."

He spent four months at Yale-New Haven. Then the turning point wasn't some sort of cataclysmic awakening?

"It was not an event or any one relationship. It was a day by day re-emergence into the world through many relationships and the support of the treatment program. I was able to come back home by late May, on passes, and then in June for good, to live at home and work as a laboratory assistant. I enjoyed the work enormously.

It's really gratifying, once you do emerge from the period of depression and uncertainty and feeling, How am I going to make it in a world which I used to hike and walk and run in? Once you start feeling powerful and competent in that world, as a disabled person, it's a great thing."



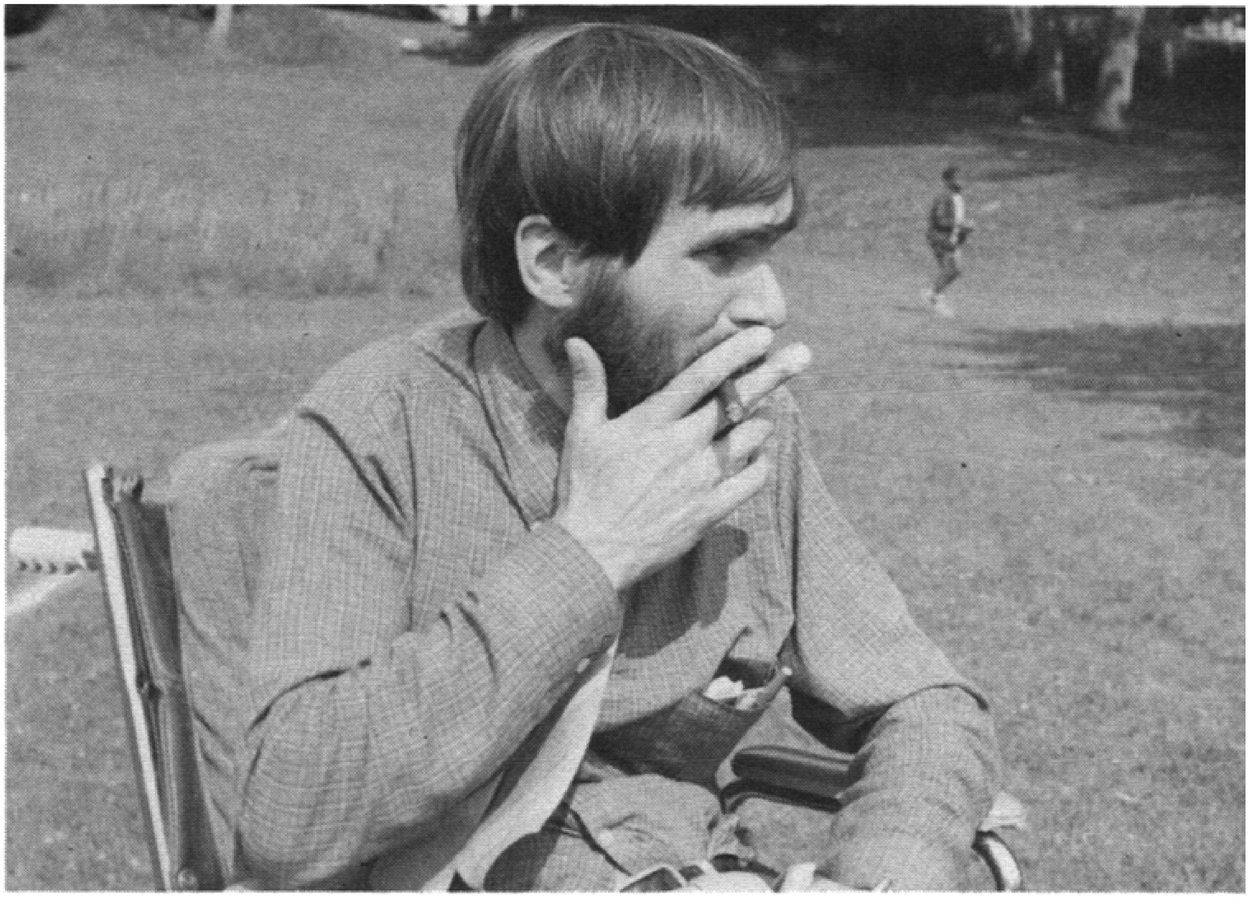
Quickie 10 years: He returned to college in 1970, enjoyed it and graduated in 1972. Spent two years in medical school, lost another girl friend, had trouble with both his bladder and school and took a leave of absence. He "floundered" (his word) around Hartford for a couple of years. "In between leaving medical school and starting working for a newspaper three years ago, I worked for an insurance company part-time and did a lot of volunteer work for the medical school. And I bounced in and out of two psychiatric admissions." Why the admissions? Bad times. It's been a long road. "During the second hospitalization, I started working at journalism again, something I'd always done in high school and college and everywhere, but I started to think about doing it as a central activity."

What does he do now? "I'm not a salaried reporter. Never have been. I'm now working as a freelancer for a neighborhood paper. I did work for two years for another paper, a weekly called the *Newington Town Crier*. I was really full-time there for a year, but my official status was as a freelancer."

Can you make it as a freelancer?

"No. I can't now. Very few people can. I'm fortunate to be subsidized by my family while I'm still doing it. The Social Security people called up and wanted to know what I was earning." When he told them he earned about $30 a week for 30 hours work, they said to forget it.

Is he a gimp rights activist? Well, after a fashion: "An issue that's important to me, as a 12 year paraplegic now, is violence. Of all kinds. I think that prevention of violence is a great way of preventing disability. Disabled people should be concerned about preventing war, as well as tooting in the legislature for the rights of the disabled. I don't think people who just concentrate on ramping curbs and getting better veterans' benefits are being socially responsible in limiting their political activities to that kind of thing. Another thing I feel is important in preventing disability —and I think that freshly injured people could and should be aware of it because they could go out to help prevent it from happening to other people —is that we need to teach people how to assess risk and how to go up close to injury but stay safely this side of it. The automobile is the third thing. Prevention of disability through automobile accidents is, in the US, statistically more important than either war or sports. I'd like to see disability prevented on all three fronts."



How about human relationships now? "I felt until 1976 that life wouldn't be very tolerable for me without that kind of crazy version of erotic love that we're taught is supposedly standard for everybody. I've gone through a big change in my attitudes towards that." He finds now that he can spread his friendships more diffusely, to more people, and feel comfortable with warm and affectionate relationships with many people from many parts of his life. Old friends, new friends, school friends, work friends, neighborhood regulars (of which he's one), and, especially, the Quaker Friends Meeting. He joined the Quakers two years ago and likes what it has done for his life.

John talks a lot about the support he gets from his neighborhood community, both physical and emotional. "You get to *see* your neighbors here, there's a lot of face to face contact and you develop rapport with them right away. I can go right out the front door and I can see neighbors, have conversations with them, feel supported and go back and not feel isolated."

Does he feel that it's important to make himself highly visible in the neighborhood? "I guess it is, just by definition, or I wouldn't be doing it. I don't do it consciously, to get out and be seen. I go out because I want to go out. But it sure is important to me, as a side effect, more than as a goal, to be seen as someone who's out rather than someone who's closeted away to be pitied. But there was a long time there years ago, where it would be hard to say which was the motivation. It was hard to do at the time. Yeah. Very scary."

6.8.5 Andy Lopez

Andy Lopez was a 17 year old into bikes and speed, a whiz kid with very winning ways at the local motocross and dirt tracks. He spent every warm weekend either racing or out riding with his buddies, usually on the maze of motorcycle trails the Forest Service maintains though the Rampart Range. To Andy, dirt riding was a passion, a way of life. It was what you did every Sunday.

It still is. Since his auto accident in 1975 (T4,5), Andy still haunts the foothills, sand washes and back roads with his biking friends. He does it in a dune buggy.

I always thought a dune buggy was some kind of lumbering all-terrain vehicle, or a crawling lunar module, or maybe a cute little minicar with a fringed canopy and built-in coeds.

Here's a dune buggy.

It's a Honda Odyssey, hand controlled, available from stock in any large city. Andy wasn't entirely satisfied with the factory model, so he shipped the engine off to California for a Honda-approved custom hot rodding job. When it came back, it was a pretty mean machine. It's extremely fast.

“You have to go fast. That’s something in me, I’ve always had in me. I got this dune buggy and I want to go faster and faster and faster! It blows some of my friends’ minds.”

I asked Bob, one of Andy’s dirt friends, if Andy slowed him down: “Him? He keeps a pace that I have to keep up with.” He went on to tell me that all Andy’s friends had tried driving the buggy, but nobody was good enough at it to make it perform. It's not like putting training wheels on a motorcycle; it's a skill unto itself because all the weight is on the rear wheels and there's no effective way to steer except with engine power. Andy's got the touch and it does blow minds.

He's also rolled it. He wears a complete racer's chest harness and ties his legs in, so he wasn't hurt. Is it dangerous? "Yeah, I suppose so. Everything's dangerous."

I noticed that Andy used a thin cushion on the bucket seat, and asked about weight shifts and the possibility of pressure sores when bouncing along a rough track at 60 miles per hour. I was informed that since the machine has no suspension and is air-borne most of the time, it *is* a weight shifter. Oh.

"There's a certain feeling about being in the dirt. There's no law, no stop, no go. Just do your own thing, which I'm into."

Dirt rider outlaw? Not entirely. Since his accident, Andy has completed his GED and two semesters of college. He goes to school two days a week and works at Craig Hospital the other three.

"I'm working with data research and interviewing patients, finding out what they're paying pre-admission to Craig, what hospitals they've been at, then we do follow-up on them when they come back to Craig."

He's good at his job. People obviously feel at ease with him, and he seems like anything except a social worker. That's a compliment.

A few one-liners:

- The wheelchair: "My biking friends *love* my chair." (They tear it up playing with it.)
- Rehabilitation: "You learn something every day. Something's hard, you keep doing it and it gets easier."

- Hot Tip: "Stay active, don't stay at home, just keep moving."

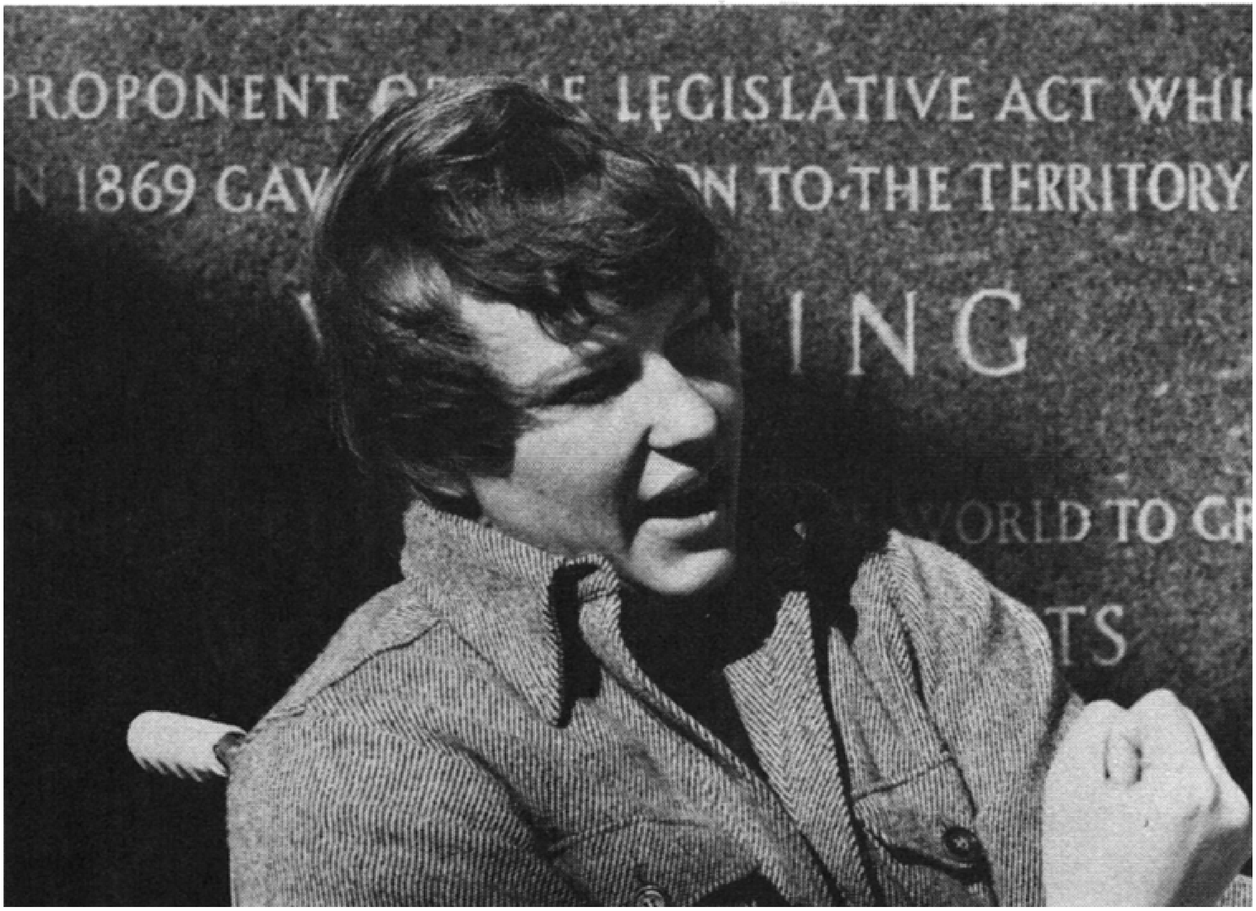
Speedy Andy Lopez, dirt bike outlaw, moving target, was last seen vrooming off toward a master's degree in sociology.

6.8.6 Lyn Dickey

How's this for a resume?

"When I first came back to the state in 1974, I went to work for the Powder River Resources Council, just a group of ranchers in the northern part of the state trying to keep the coal development in that part of the country under control. I did that (read, she *ran* that) for three years, then I took a short summer job doing some water research for Senator Malcolm Wallop, who had just been elected from Wyoming at that time. And from there I came down to Cheyenne and went to work for Governor Herschler as the director of his Energy Conservation Office, did that for a year and a half, and now I'm working as his legislative liaison. And as soon as I'm through with this session (of the legislature), I'm planning to hit the road and just travel for a few months."

She forgot to mention that the governor also appointed her to the Environmental Quality Council, which oversees all the state's environmental laws. Not bad for a hometown kid from Buffalo, Wyoming.



Back to 1966, when Lyn was 17. She was in a car wreck which left her a T8 para and her mother a quad. When I made the mandatory comment that some people had all the luck, she conceded that it was a major experience for the entire family.

Lyn was pretty beat up, so she cooked up a few projects to pass the time while she was recuperating. She finished her junior year of high school by sending recorded tapes back to her teachers in Buffalo. She also launched a political career.

"I tape recorded a speech of all the reasons they should elect me student body president, and they played it at the assembly where all the other candidates gave their speeches. Sympathy vote didn't make it, though; "I came in second."

She spent the summer at Craig Hospital, and, come autumn, was back at her old high school in Buffalo.

"The Johnson County High School has about seven levels, with worlds of stairs among all the levels. So all the football players in my class—they loved it — there were contests to see who could get me up and down the stairs the fastest. They would *run* up and down the stairs, which is probably why I have not the least qualms about being hauled up and down stairs by much of anybody."

She graduated, worked in a local bank that summer and went to the University of Illinois. She graduated as an English teacher, a profession she hasn't really exercised, and went through a second spinal fusion and an aortic repair somewhere along the way.

Lyn's first career decision was to get into some sort of voluntary service, so she asked VISTA and the Mennonite and Jesuit voluntary services. "The Mennonites were the only ones who seemed to feel, like, they'd never *had* anybody in a wheelchair before and didn't really know what I could *do*, but they figured that if I wanted to try it, they'd take me. So I moved to Wichita and worked for a year in a house full of other volunteers."

In addition to serving as receptionist, secretary and fund-raiser to the voluntary service, she worked on a few other interests:

- She taught adult education at night for the Wichita school system.
- She organized the Wichita chapter of Common Cause.
- She fought a nuclear power plant, and won.

The Mennonites may think twice about their next gimp.

Her next decision was to move into citizen action, so she paid Wyoming a visit before heading to Washington, DC, which is where she figured citizens went to get active. But fate, or whatever, delivered her to a board meeting of the Powder River Basin Resources Council, whose only staff person had just quit.

"So I figured, why go to Washington DC? These guys need some help. Convinced them that they should hire me, and just fell right into it." And so began the five year saga of Wyoming's *enfant terrible*. The rest is *not* history, for I suspect that Lyn's upcoming sabbatical is simply the calm before the storm. In the meantime, here are some glimpses of whatever it is that makes her tick so dynamically:

Did the governor first appoint her because she was a woman? "Doubtful." Because she was a paraplegic? "I don't think he even *knew* it." She goes on to say that she thinks she was appointed because she was perceived as being a "reasonable radical." Huh?

Once Lyn had the Energy Conservation Office set up, she grew restless with the job because it was primarily educational and "because there were no real political fights going on, and I miss the head-butting." So…

"I got the governor to hire me to be his legislative liaison for the session. Plenty of fights here. And the legislative session surely is a time when you've got plenty of dates certain— you've got a battle that has a time when it's won or lost."

Here's what a legislative liaison person does: "See that the bills he (the governor) wants to have passed are moving through the process as best they can. Letting him know where they are, letting him know who's taking what position on them, getting information to the legislators at his request or at their request — basically, just to track the legislation for him."

But… "It has not been nearly as satisfying a job for me as lobbying for Powder River, because there's no identifiable constituency. You just have the governor and you have, theoretically, all the people in the state."

She has an interesting sense of context. Here's what she feels about her accomplishments of the last five years: "I have attempted to influence the political history of the State of Wyoming, and I've probably had an influence on it. I've spent the last five years of my life basically trying to help keep some controls on the growth of the mineral industry in the state, and yet for all I know, it might have been far better if I hadn't done that. The best thing in the world for getting things back to a degree of sanity in this country might very well be to just continue the exploitation as fast as you can and with as little thought as you can so that you reach the critical point sooner and everybody can turn around and head in the right direction. I think that people who feel they are influencing things in the direction they *seem* to be influencing them, they may be right and they may not be right. It's just a way to spend your time. Really. Everybody has to do *something*.

"I want to be sure I keep my grounding in the things which I think are truly important, which have nothing to do with energy or politics, but with just living and sharing yourself with people and being there."

Lyn obviously knows a great deal about dealing with people, but she's not immune to the reactions of others to her chair: "Everybody you run into, the first thing they notice about you is that you're in a wheelchair. There are people who don't get over noticing that as being the most important part of you. And these people —they're simply people you'll never get to know. I think that's true of most any individual. Some people can't get over the fact that you're *bald*."

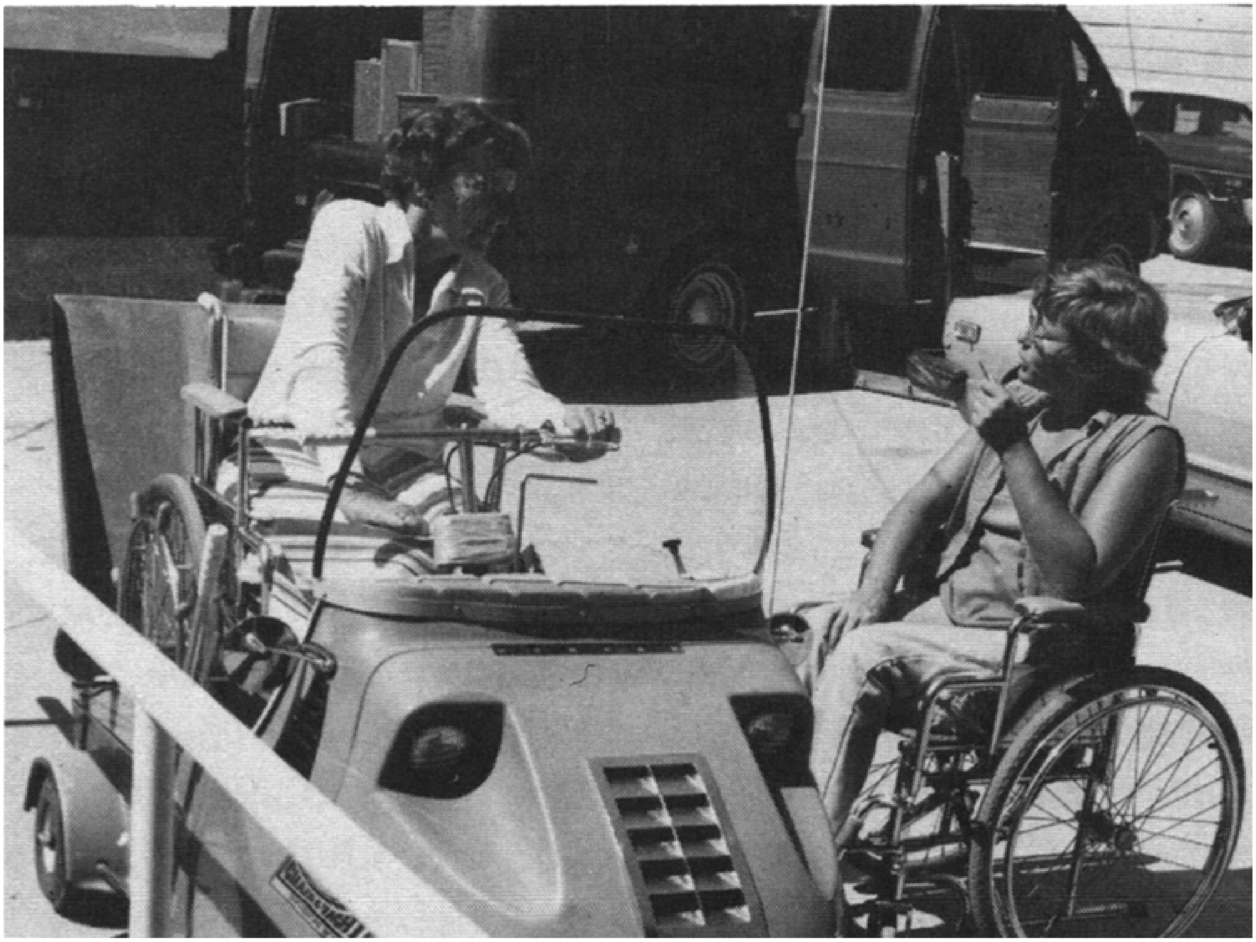
Her work requires her to do an astounding amount of travel, which she loves. I asked her about practical problems: "I think it's downright handy to have a catheter in you when you're spending a lot of time on the road, because you can just pull over and hang your bag out the door. Now on an airplane, it's much more difficult, it's true. There's no really acceptable way to go to the bathroom in an airplane. When it becomes necessary for me to, I simply pee in the throw-up bag and ring for the stewardess. And none of them ever seem to object, to tell the truth, but I find it somewhat embarrassing."

And about the Privilege of Paralysis: "A lot of times you'll get asked to move to the front of the line so you don't have to wait, when obviously you're better equipped to sit in line than most of the people who are standing up." Cops are nice to her, and although she's been stopped numerous times, she's never been given a ticket. "I've always felt that the first cop that has the guts to give me a ticket when I'm speeding, I'll be forced to congratulate him for his courage."

Update: Lyn, when last seen, had just been given a ticket for speeding. She did not congratulate the patrolman. She was leaving the next day to lobby for Powder River in Washington, DC.

6.8.7 Imogene Dickey

Buffalo, Wyoming, is a three-stoplight town on the east flank of the Bighorn Range. It's an old town with wide, shady streets, gracious houses and the beginnings of the energy boom starting to show around the edges. It's still the kind of place small town lovers love. We've come to the home of Will and Imogene Dickey, longtime residents. There's a ramp in the back, a beat up VW bus with a lift and a Chair-E-Yacht. This last is a powered trike which will transport a wheelchair and its occupant. It's designed and manufactured in Shoshoni, Wyoming, a town lots smaller than Buffalo. And best of all, Lyn Dickey is here on a visit. Her story precedes this one.



As previously reported, the Dickey family won the paralysis sweepstakes back in 1966 when a car wreck left mother Imogene a C5,6 quad and daughter Lyn a T8 para. Imogene was 42 then, with four children. From her account, the accident was hilarious…

"We just did the old roll, three or four times, and she and I ended up under the car. When the wrecker from Gillette came out, finally, to lift the car off of us, it just got the winch hooked up and was out of gas. I always thought that was neat. The wrecker ran out of gas."

Were there any guilt feelings about the accident? Lyn: "*Everyone* felt guilty. I always figured I was the only one who felt guilty, because I was driving. I didn't find out 'til years later that Mom felt guilty 'cause she decided on the route, Dad felt guilty ’cause he didn’t go, and (brother) Dave felt guilty ’cause we were coming down to see him. A friend felt guilty ’cause she had had a dream the night before that we were gonna wreck, and she didn’t tell us…”

Imogene: “But I tell you, the guy who took care of that was Will (her husband). He said to *forget it!* You don’t do anything but use up a lot of energy and make people miserable, worrying about what you should have done. There’s no way to go but up. And the more time you spend dwelling on things that might have been, the less productive life you’re ever gonna live. And Will just got that across to Lyn and me both.”

Lyn: “I think it’s true that Dad was instrumental. He always had taught us, and continued to teach us, *Wherever you are right now, that’s where you are. That’s what you deal with.*”

After seven weeks in a general hospital and five months at a SCI unit, both were back home in Buffalo. While Lyn was being run up and down the many stairs of her high school by eager football players, her mother was having a different experience.

Imogene’s first challenge was being mother to four children, one of whom was a paraplegic. “The biggest thing was frustration. Absolute frustration. In the morning, when the kids would all get off to school, I’d come to this kitchen door and see every conceivable surface covered with something. I hate clutter. I have to have a neat place to have a neat mind. So I got in the habit of backing in so I couldn’t see it all. I could do it, one thing at a time, but if I had to look at it all, I couldn’t see how I could ever make any order of it. So I just backed in.” (Maybe that’s how we should all approach our injuries: *Back* into coping. One thing at a time. The parts, taken singly, can be less than the whole just as the whole can exceed the sum of the parts.)

Their doctor’s wife intuited that Imogene’s return home might be a difficult time. “So she had this bunch of gals, about 10 or 12 of them, and every day one or two of them came in. Each morning. Not to work, necessarily, but just so I’d be up and in here and talking and living. And they did that for years. I feel like I have the greatest bunch of people around in the world.

“You expect your family to rally around and be what they should be, but your friends are the ones that keep you going. They expect you to do things, and you just don’t want to disappoint them. You don’t really have any choice. You either roll over and play dead, or you stay in the swim of things.”

Buffalo winters are cold and deep. How does she deal with below-zero temperatures and all the snow? “Everything I belong to, as much as I can, I ask them to meet here in the winter. It works out well. So I have Musical up here a lot, PEO, anything, any committee I’m on, Republican Women’s Club meets here regularly, and that’s great because that way I can stay active without having to go out a lot in the winter time.”

How about your church? “It’s as important a family to me as my own immediate family. I feel that a church home and a church family is an absolutely essential ingredient in my life. I feel a closeness to my church.”

Lyn points out that this kind of support, from friends, membership groups and church, would be less available in a larger town. It’s an interesting trade-off. So many of us have moved to the warm weather, the flat terrain, the accessible architecture, or just to be near a hospital or rehab center. Imogene has stayed on in a small and remote mountain town with vicious winters, steep terrain, few architectural amenities and only the usual rural health care. Although she didn’t say so in as many words, I think she’s decided that her roots are worth more to her than her convenience. In these mobile days of scattered friends and families, few of us can find our roots, let alone treat them with love and respect. There’s some nice values operative here. Yet Imogene does admit that spending some time in San Diego each year would go a long way toward tempering the impact of Wyoming winters.

Now that her four kids are out the door, and she and Will are once again the chief boarders, she's written and published a cookbook, *Recipes and Cooking Hints for Brides and Other Handicapped People*. The title alone is worth the paltry price, and the recipes are what you make of them. Literally. Here's a gem from the preface:

"I believe the shucking of false pride was one of the most difficult things I had to accomplish. Finally I accept that although I may not like it, one of my chief responsibilities as a physically handicapped person is to help able bodied people. Help them feel comfortable, help them feel useful. I have long known that the only truly happy people are those who are lovingly doing for others. So I do all I can, but try to accept help graciously for the things I can't."

The *Joy of Cooking* doesn't have anything that good in it.

6.8.8 Bob Felker

In 1968, Bob was 20 years old. He had a high school education, some additional technical and auto mechanics training and a Louisiana accent thick enough to cut. And after tangling unsuccessfully with a forklift, he had a broken back. He's a T10 para.

Bob would be described down south as a good 'ol boy. He's a wiry man, with deepset eyes that look at the world with a twinkle from somewhere way back in his head. I can never tell when he's pulling my leg or being serious, and I usually feel that he's doing both at once. His life is pretty good right now, but it took him a few years of searching, after his accident, to find his new self.

"The hardest thing was goin' out into the real world after I was hospitalized for 14 months. During this time I never had any real interaction with the outside world —I was so used to the hospital type of setting and the other spinal cord injuries, other wheelchairs around all the time. Goin' out in public by myself, goin' to the grocery store, shopping, anything, just bein' able to cope with the general public — that's the roughest thing.

"I can handle it now. I just look at all the things I got goin' for me, and depression doesn't stand much of a chance of lastin' very long."

Bob was particularly self-conscious about his wheelchair. He didn't like it, and he figured strangers didn't like it either.

"I had to realize that if people do look at me, it's probably out of curiosity. I like to think that maybe they're *admirin'* me. They're admirin' the things that I do. And I show off, pull a wheelie or somethin', so they can really admire me.

"Kids are neat. They're really innocent and they're not afraid to ask questions. I remember one little kid asked me one time why I was in a wheelbarrow, and I thought it was funny and I explained it to him real good, sure did."

As his dealing with the public became more skillful, he started working more energetically on personal relationships. Sex was a problem, and he dealt with it.

"At first I didn't think I was capable of *any* type of sex, and I believed that if I couldn't have sex exactly the same way I did before I was injured, in the 'normal' way, then it wasn't sex. Now I've learned different techniques, different feelings, learned to recognize my feelings … my sex life now is better than it ever was, it really is.

"Met this girl, she really kind of turned my head around and made me realize what life was all about and how interestin' it could be and how good it could be. For the last year or so, I've really been high."

Bob now lives in a house by the foothills, shared by two paraplegics. "Won't be livin' there too much longer, hopefully, 'cause I'm going to be gettin' married, get me a *new* roommate."

Along with marriage, education is a high priority in his life. “I came up here from Louisiana with schoolin’ in mind, and that’s what I’ve been doin’ the last two years. Goin’ for my bachelor’s in human services and planning to do graduate work in rehabilitation counseling.”

What’s it like going back to school?

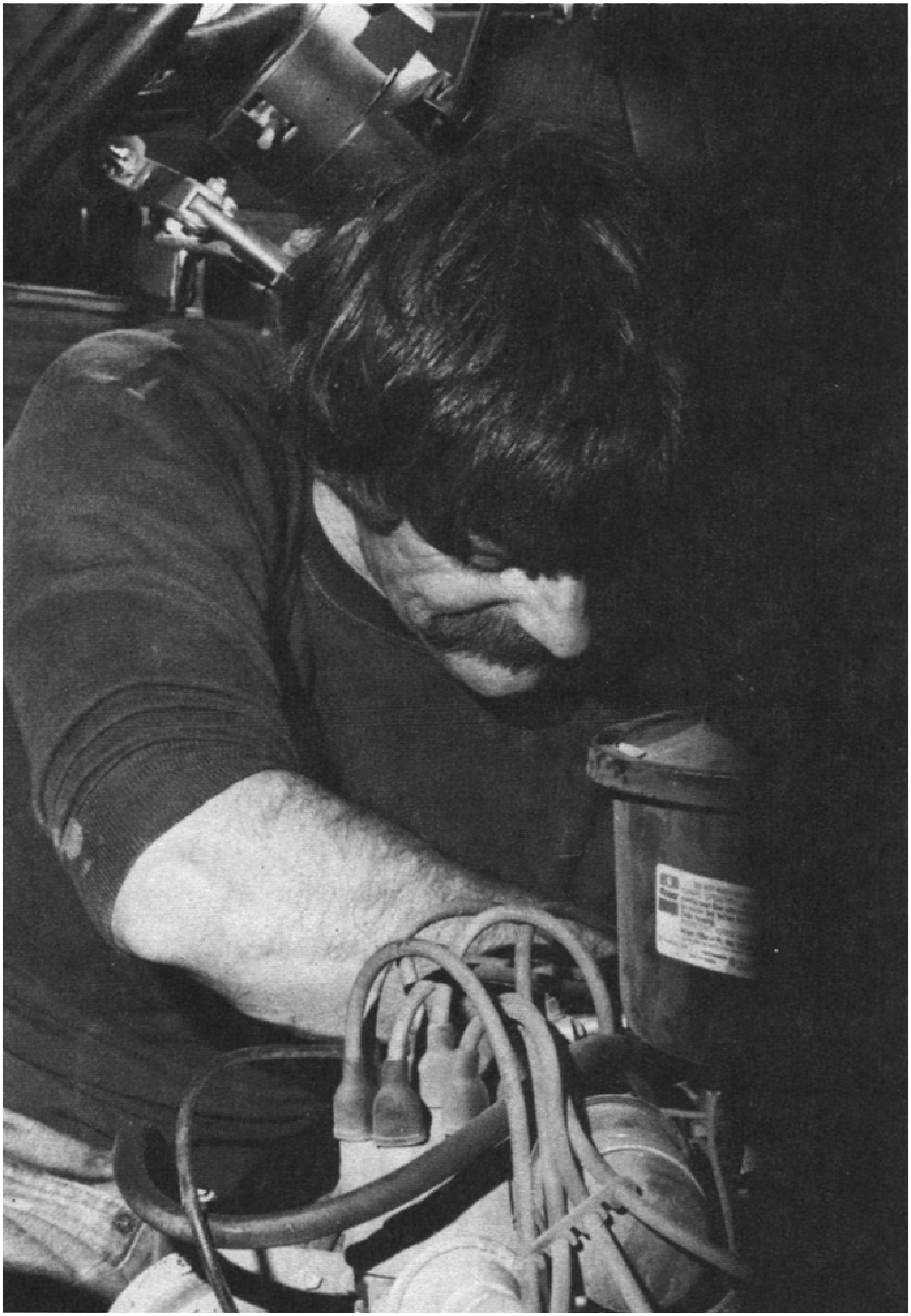
“It’s a bummer at first. After you been out so long, and of course goin’ to school with kids a lot younger than you is kind of a pain, too. But after the first semester you’ve pretty well got it whipped. It’s fun, it sure is.”

Bob may be on a winning streak, but he still needs to live until he gets his degree. He does this by plying his old trade, auto mechanics. He specializes in mobile tune-up jobs, but works on any part of a car that needs fixing. He's earned a local reputation as a top notch mechanic. Like many of us, he faces conflicts with the Social Security system.

"Social Security is a real booger, it sure is. It destroys your incentive to work. I make $264 a month Social Security — that's my total income —if I go to work I stand a real chance of losin' this income plus losin' my schoolin'. So I have to do this auto mechanics on the side to supplement my income in order to live, and I got to do it under the table."

About his work? "I like it. I like to be able to say that I can do it. It's kind of an ego trip and it also gives me a sense of self-worth. Lots of times an able bodied person'll come to me and ask for advice or for my work. I may not be able to do some of the things he can do, but I can do some things he can't do. I get enjoyment and fulfillment out of that. I like to see the results of my work, like all mechanics, cause I *can* see the results. I'm not goin' to do it the rest of my life; that's why I'm goin' to school. I'm tired of gettin' my hands dirty."

Today, Bob has braces on and is draped over the engine of my '73 Ford. He's just fixed a post-ignition problem it was having. He stands up beside the car, looks at his hands, and delivers his manifesto:



"I'll get me a degree, get me a secretary. I'll let somebody else get their hands dirty. This stuff's alright for amateurs, but I'm goin' to be *pro-fessional!*"

Here's a story Bob told: "About two or three feet high, the grass was, and I was sittin' right in the middle of it in my wheelchair fishin', and somethin' started comin' at me through the grass. And the way it was movin', it looked like a big old snake, it sure did. Tried to turn around to get out of there, and when I did my front wheels fell in a hole and I was stuck there and this thing kept comin' closer and closer —really gettin' close. When it was about 10 feet away, I was so scared that I just made a superhuman effort and jerked my wheels out of the hole and got turned around and pushed all the way back to the road and this thing was following me all the way. It came out of the grass and it was a cotton pickin' armadillo —big 'ol armadillo, as harmless —it sure was. So I tried to chase *it* and I was goin' to *get* it and *eat* it. Sure was. But I couldn't ketch it, sure couldn't."

There's a moral here somewhere about snakes in the grass and things appearing scarier than they really are, but Bob would be the last person to bludgeon us with it…

6.9 Half Way Progress Report

(or: How to Have Fun with Your Most Hideous Moments)

(or: Motley Thoughts, Black Holes and Mild Exultations)

I venture into this book with closed and lifeless eyes, because I am afraid of finding in others what I dread to find in myself.

I venture into this book keen-eyed and alert, because I am sure of finding in others what I hope to find in myself.

Oops. Perhaps the chaos inside is visible. I'd better hide. But what if somebody sees me? The only thing worse than being discovered is to be discovered *hiding*. The mind is a crazy place; dangerous territory.

Where is the reset button on this machine?

When will amnesty be declared?

Piss and moan. Bitch and Begrudge. Poor sport.

Tonight I go out of my way to ensure that everything is just as bad as I think it is. I want to hurt exquisitely, because it identifies my uniqueness and is better than hurting without distinction. My paranoia glows with a light of its own, and Oh my, the baddies are out again tonight.

A few moments ago, I took this little depression I'm having here outdoors for inspiration. There are flowers and trees and mountains and valleys out there, and sometimes it works. Tonight it rained and my pen dried up. This problem has nothing to do with paraplegia.

My Sense of Deepest Personal Tragedy is grandly romantic. I imagine myself to be on the Very Rim of Darkness, the Last Edge of Light. Walls of Trivia confront and confound me. I am having a Wonderful time being Deliciously Morose.

Still … I once heard of a quad who bit his thumb to spasm his wrist out of an uncomfortable position. Can I spasm my psyche?

Sure. Just take a little Transmutation of Energy potion, and all that negativity changes valence and becomes unstoppable positive energy.

It starts slowly. There is a tentative, almost furtive reach of hope. But hoping, says my Internal Central Security Censor, Cynic and Spoilsport, is the most childish of sins. It's like praying to God for candy instead of grace.

Doing is much, much easier than hoping, because you get something done. Now that's profound. Really.

Doing can be instigated by negative events and feelings just as well as by positive ones.

Doing results from interest, attraction, hope, love.

Doing results from disinterest, repulsion, fear, hate. Is one set neurotic, yet not the other?

Doing is what we need to do.

What shall I do? A project, a prospect, a love, a life, a job, a journey? They all contain threats equal to their promise, so I constantly meet both ends of the stick head on—the joy/sorrow bleepstick of life. I'm beginning to like it.

Ecstatic rape.

A sense of humor. A sense of privilege. That's the ticket. It's not such a warped idea, either, this sense of privilege. Do you know anybody you'd trade lives with? Not bodies, legs, or jobs or wives, but *lives*? Your own identity?

Gratuitous information department: Did you know that you can become unafraid of fear? You can. I know. I've done it. Fear is like a headache; if it happens, it happens. But there's nothing *scary* about it. Not any more. That much, at least, has been accomplished.

Lethargy and energy seem like opposites, but they actually require equal amounts of Lethenergy to manifest themselves. Do you have lethenergy? Yeth.

Enigma pie.

6.10 Friends and Relations

6.10.1 Friends

All your friends gone? Deserted you? Don't like gimps?

It's easy to feel alone. Let's assume the unlikely worst. You *are* alone, or virtually so. Your old friends have lost interest. What is difficult to see from your perspective as novice wheeler is that you can't *move* in this world without meeting people and forming relationships. The only social tragedy which can befall you is not to move, to hide yourself. If you are visible, if you see *anyone*, then the only way you can prevent social ties from forming is to not want them.

> "If a person can learn to like himself enough to project that feeling of good feelin' about himself to other people, then it's just a matter of time before the other people are going to come around and get to like him as a person. They're not gonna look at that wheelchair anymore — they're gonna like him as Joe or Bill or Suzanne of whoever."
>
> —Rick Harry

6.11 Coitus Interruptus, Pure Sex and Prurient Interests, No Love

> "If you think paras or quads are safe, I suggest you don't let your daughters go out with paras or quads. Because they're *not*. Did you hear about that para who was sentenced to 20 years for rape?"
>
> —Steve Epstein

Sex for the disabled is a subject that was ignored for decades because of prudishness, because nobody wanted to embarrass the sexually handicapped, not to mention the many health professionals who were therapeutically impotent, because ignorance was thought to be bliss, and because professionals made the unbelievable assumption that reduced physical function indicated reduced sexual need.

Today the pendulum has swung with a vengeance, and the ability to express sex needs has been recognized as one of the cardinal rehabilitative factors. The new SCI may well be bombarded with how-to-do-it books, SAR's, offers of prosthetic erections, sexual surrogates, discussion groups and one-to-one sexual counseling. The Significant Other now reigns supreme. This onslaught is extremely helpful to some, extremely distasteful to others and is therefore a subject I won't touch with a pole of any length. The literature is available, and some of it is noted in the bibliography.

SAR’s can be located through the Regional SCI Centers. The rest depends on what your rehab center offers, what you want and what you feel you do or don’t need.

In interviewing the people in this book, I did not ask for a lot of sexual candor. Some wanted to talk about sex; others did not. It is possible to pull together a few observations.

Most feel that, after some initial hesitation and experimentation, and sometimes after a difficult adjustment to an altered body image, forming sexual relationships has become as easy or as difficult as it was before. They feel no change in their ability to attract partners or to satisfy and be satisfied.

Virtually all of us feel that sex, not sexuality, has changed. Sex is less of a tumultuous release and more of a prolonged sharing. There are changes in techniques used and partners chosen.

> “A woman that’s really good with my ears can just make me do anything for her all night — she’s got me forever. That’s important, and I have to let a woman know that, because a lot of women aren’t into ears. They just aren’t!”
>
> —Rick Harry

Oral sex assumes a greater role for the obvious reasons of manual and penile dysfunction. Since many AB’s are put off by oral sex in the active sense, and since almost nobody is put off by oral sex in the passive sense, our own position in the home bed or the sexual marketplace is enhanced. He or she who gives generously shall be generously rewarded. In this lifetime!

There is an appreciation of appreciation. You can take joy in your partner getting off, even if you’re not getting off. You can take so much joy that you *will* get off. Somehow. The operative factor is receiving pleasure from someone else’s pleasure. This leads to a closeness and shared awareness of needs which is often lost in the explosive urgency which usually dominates the AB’d male. And since you’re probably not prone to premature ejaculation, you’re once again a hot item because you can keep going all night. To a SCI’d male who thinks he has lost his sexual power, nothing is more restorative than to witness and share as many orgasms as his partner wants to have. The SCI’d woman’s point of view is best expressed by a woman, and I recommend Sue Bregman’s ISexuality and the SCI”d Woman*. Here’s more from male to male:

> “(There’s a prevalent belief that) if your neurology is such that you do not get an erection physiologically, then you must have an erection prosthetically. I have no objection to this procedure, but I do object to the procedure being offered to newly injured people who have not had an adequate trial at living an integrated life as a para or a quad, who have not learned to *like* themselves again, who still see themselves as some kind of abomination, who think the big thing in sex is genital activity.”
>
> —George Hohmann

> “Before, I never took the time with a woman. I never really gave to her; I wanted. Now I find that by giving, it gives back one hundred times over. Makin’ love with a woman is priceless.”
>
> —Rick Harry

Some of us turn to lustless, but not lusterless, affection. Relationships can flourish on other kinds of energy:

> “Sex is the most direct form of communication between people. And to feel that that’s thwarted is horrible. But what you realize is that real communication doesn’t depend on just that one gimmick. It’s possible to reach people intimately on all channels, not just one.”
>
> —Binny Clark

A few of us have become sexually apathetic, and successfully directed those energies elsewhere. This is not failure, for the sublimation of desire is a time honored solution. Perhaps if the physical juices are diluted, then the emotional and intellectual stews thicken.

A very few feel that reduced sensation and function have rendered the sexual experience boring. It’s all give and no take, and their itch seems unscratchable. This is more likely a failure of relationship than of sex, but it *feels* like a sex problem. The cure is obvious but not necessarily easy — get into someone else’s head and body.

Since even the sexual information explosion of the seventies maintains a profound silence on the subject of disability and homosexuality, I want to state that at least one woman and three men in this book are gay. There are many whose preferences I don't know. The point is that the disabled population faithfully represents the composition of the AB'd population from which it sprang, so if Kinsey is correct, 10 or 15 percent of us are gay. The only counseling for gays I found was, not surprisingly, in Berkeley. Ask at CIL. If you're not in Berkeley, just ask. Don't hang out in emotional drag just because you're gay and gimped. You're not alone.

It must be recognized that we're all different in what we can do, what we need to do and what we need to have done. There is no sacred standard of performance to live up to.

Finally, this is about sex, which is only one of the rewards of relationship. The real story is still, as it always was and will be, people interacting with people. Sex has been pried loose from the totality of relationship, in this case, only because most of us once worried about our ability to attract and perform after our accidents, just as we did when we were teenagers. Some of us are doing both, simultaneously developing a sexual identity and a new body image. These are permissive and experimental times, good times to learn or re-learn about sex. Disabled or not, sex is the easy part of a relationship. Don't be afraid of it.

Sex is the Sabre Toothed Guppy of SCI.

> "So many people never used to think that a person in a wheelchair could have any kind of relationship on a meaningful level, and now people understand. Yeah, Hey, this guy and this girl, they can be good lovers. They *can* have good relationships."
>
> —Rick Harry

6.11.1 Love and Relationship, No Sex

> "You meet in your lifetime, 10,000 women, 500 of whom are remarkable in your own estimation, 100 of whom you can get to know a little bit, and five of whom may be candidates for a long term relationship. When you narrow it down so much, it seems to me that this unique condition doesn't really move it one way or another."
>
> —W. Mitchell

It should be obvious by now that paras and quads of both sexes fall in love, have affairs, get married, have homes, raise kids, have lasting relationships and get divorced just like everybody else. There is *no* reason for loneliness to be the absolute condition of our days.

Why should it? The people in this book tell it the way it is, and I have no reason to embellish. Relationships are the most important part of most lives and relationships are a large part of what this book is about.

6.12 Lives V

6.12.1 George Hohmann

We're in Tucson, sitting in a pleasant backyard patio chatting with George Hohmann. This man is pretty special, and I'm curious enough to start off with a direct question: George, you've been in that chair for 35 years. Has it been good or has it been bad?

"It's been good." And to George Hohmann, life surely has been good. You can see it in his face, which looks much younger than his 55 years, and you can see it in his satisfaction with home, marriage, children and career.

His career is mainly what the world sees, although he seems to have several careers. He's just finished 30 years with the Veteran's Administration, most recently as chief psychologist for the Tucson VA Hospital. He's now planning to intensify his involvement with the University of Arizona, although he already holds a full professorship. He teaches courses in abnormal psychology and psychopathology, heads a psychodiagnostic testing assessment seminar, sits on a number of doctoral committees, directs dissertations and supervises clinical work. He crosses the country about once a month giving lectures and participating in seminars and symposiums. He has written papers on many aspects of disability, and, although he vehemently rejects the appellation, has been described by several of his prominent peers as the Father of Rehabilitation Psychology. He is, he'll admit, a workaholic.

In 1944, when he was 20, George had survived the dust bowl days of the Texas Panhandle and was hoping to survive World War II. He took a bullet in his spine, had a T9,10 lesion and lousy expectations. "In 1944, there were no wheelchairs on a SCI ward with 60 people on it. The army would not invest in these wheelchairs because we were all gonna be *dead*." So George was once again faced with a survival situation and took matters into his own hands.

He started school at UCLA in 1946, which was, at the time, a pretty outrageous thing to do. "People who were disabled, crippled if you will, stayed at home or in institutions, hospitals, nursing homes —they didn't mess around out in public."

George messed around a lot. He married in 1948, even though prevailing wisdom strongly suggested that wheelchairs and marriage don't mix. The marriage is still strong. About the same time George collected his PhD, he and his wife adopted the first of two children, both now in their twenties and in graduate school.

[It's interesting to note that in those days, the Hohmann's were told that a disabled man was an unsuitable parent. It took years to beat down the resistance of the Children's Home Society. In contrast, check the ease with which the Ludlows, a quad and his wife, adopted their children (see *Bob Ludlow*). Times have changed, partly because of people like George.]

Does he recommend adoption? "The adoption experience itself was very very rewarding. I don't see how people could love a kid any more if they had borne them. I don't know how there could be any more relationship with the kids than we have had."

With wife, kids, doctorate and a job with the VA, George started messing around in the field of rehabilitation and took a strong interest in the psychosexual problems of returning veterans: "I think of people who are into human sexuality as kind of kinky people in general, and I think of myself as one of the straightest people I've ever known. But one of the problems was that the patients were saying over and over and over again, for God's sake won't somebody tell me what my sex life's going to be like, and nobody would. There was nothing, prior to 1970, that dealt with What do people do, who have cord injuries, to make love? And how do you go about making love, no matter what your neurological condition is, or how do you incorporate whatever residual genital-sexual functioning one might have into a lovemaking pattern?"

George broke the professional ice by presenting a paper that addressed these problems, a paper which has been published and reprinted and become a certified classic. So that's how George Hohmann, self-proclaimed straight, got into the sex business.

He dislikes "the assumption that the only kind of sexual activity that is desirable, that is effective, that is satisfying in the final analysis, is penis and vagina in a missionary position. I'm not putting down genital activity — it's neat, it's physiological, it's biological — but I'm saying that sex is a many splendored thing and there are lots of ways of showing love and affection. To put that much emphasis on the genitals, it seems to me, is to bastardize the beauty, the closeness, that come from a mature relationship between two people."

Of the newly cord-injured person: "They don't understand that somewhere down the line, rehabilitation probably *ain't* learning to do well what the doctor tells you; it is learning to do well that which you want to do. Maybe doing what the doctor tells you works and maybe doing the opposite works and you may have to tell him to go to hell. He is telling you how to be a patient, and if you follow all of his instructions, that's what you'll end up being. If you don't follow all his instructions, you may end up being a human being."

I submit that it is a measure of the respect and reputation he enjoys among his peers that, after 30 years of close professional association with doctors, he has not been most foully murdered in his sleep for his irreverent attitudes. Here's some more:

"Life with a disability doesn't have to be *any* way, except the way that you make it. Sure, there are reality things that one can't do, but if you can't do it that way, there's another way you can approximate doing most anything you want to. If you keep trying, if you are active, if you keep yourself exposed to other people, if you seek stimulation of one sort or the other, you're gonna get rewarded for it."

About his own life: "The most unusual thing about my life is that it's been so usual. We're the average middle class family. I've had a good career, I've had a good wife, I've raised, together with my wife, a couple of kids that are fine youngsters, had the nice things of life and I've lived! It's not everything, but it's damn sure something."

Parting shot: "SCI, like life, is an absurd kind of situation. And the only thing to do with absurdity — there are only two options— one is to laugh and one is to weep."

The latter of which is patently absurd.

6.12.2 Jonathan and Sharon Wilkin

They've been married for 14 years. They're both victims of murderous acute-phase care, both C5,6 quads, both completely independent, both graduates of the University of Illinois and both successfully and significantly employed. And they're as unalike as any two people could be. Jon: taciturn, expresses himself with shy/dry humor and precision. Sharon: lushly assertive and verbal. Their marriage, their lives and their home in Vienna, Virginia are all the results of a lot of caring and a lot of work.

1958. Sharon was 17, an exchange student newly arrived in Belgium, when she broke her neck on a ride at an amusement park. Perhaps from a need to quickly remove their casualties from the public eye, the park officials refused to let her wait for an ambulance and sent her off to a doctor sitting upright in a car, her head bobbing on her chest.

1960. Jon, riding a motor scooter, collided with a car making an illegal U-turn. He broke his neck and his arm, but had no paralysis. He was given emergency treatment at a small hospital in upstate New York where his arm was set but no X-rays were taken of his neck. After a night of tossing and turning, he was paralyzed.

Sharon stayed in a Brussels hospital for six weeks, then flew directly to a New York state rehabilitation center. She spent nine months there. "I learned to brush my teeth and wash my face and when I was discharged,

I was told— or my parents were told—that *she* would need 24-hour a day attendant care for the rest of her life." Sharon was unimpressed.

Jon, after acute care, went to a different rehabilitation hospital in the same state, where he was similarly unimpressed. "I could do the same kinds of things, like brush my teeth." And smile a lot? "No, you couldn't do that. I was supposed to brush my teeth all the time!"

Separately, both Jon and Sharon had heard that the University of Illinois at Champaign was the only university in the country then accessible to students in wheelchairs. It was accessible because of the fiery determination of one man, Professor Timothy J. Nugent. In those days, Tim interviewed all potential scholars before acceptance.

Sharon: "He's my great, great savior. He is the person to whom I attribute my entire life. And the interview with him was: Can you dress yourself? No. Well, why can't you?"

When Sharon arrived in Champaign for her first semester of school, she was put through a make-or-break functional training week. In that week, she became almost totally independent. In one week, she overcame the inertia of a year of being told she couldn't do things.

Jon: "Tim Nugent and I got into a real shouting match. Yes you can! No I can't! Yes you can! Except it took me three years instead of a week to learn to do things." (Jon has less sensation and motor function than Sharon, and spasm which he learned to deal with only after a temporary alcohol block.)

By 1965, when Sharon had her M.Ed. in counseling and Jon was finishing his master's in mathematics, they got married and moved into a modified trailer home.


BREAKING THE BARRIERS

Sharon: “It made me very angry for people to ask before we were married, Well how are you going to cut things, how are you going to handle hot things, how are you going to do this? And at that time, neither of us drove and neither of us thought we would ever be able to drive, because of our spasms. (Sharon now drives a van, and Jon, a much-loved convertible.) Now, as I look back on it, it almost horrifies me to think of what Jon and I went ahead and did without having any answers.”

Jon: “But a lot of the time, people don’t try things because they don’t know how they’re going to do them, and they’re afraid to experiment with different things.”

Do traditional gender roles get changed? What I’ve seen so far is that both of you make money and both of you make coffee.

Jon: “It’s a lot more traditional then she’d like it.”

Sharon: “Yeah! (Jon chortles softly) Now this is a serious problem. Jon was raised in a family where the mother does all of the women’s work and the father doesn’t touch it. And Jon was raised to see certain things as women’s work and certain things as men’s work. Because of Jon’s disability, and the threat to his masculinity, I did really back off pushing that he do more of the laundry, cooking, cleaning things around the house.”

Sharon admits she’s a willing martyr, and points out that it was Jon who had gotten up at 5:15 this morning, this Fourth of July holiday, to wait in line for gasoline.

Once armed with a degree, Jon spent five months searching for a job. Northern Virginia Community College finally gave him a conditional contract for one summer of teaching, and has renewed it for 11 years since. He teaches both mathematics and physics. They think his difficulty in finding a job was outright discrimination and feel sure it wouldn’t happen again now.

Sharon: “He would be sought after by industry now. They would love to have him.”

Did you ever consider switching?

Jon: “Nope. I love my job. I really do.”

After moving to the Washington, DC, area, Sharon worked as a rehabilitation counselor for eight years. In 1976, when the Department of Labor was staffing for the upcoming Section 503 contract compliance enforcement, she applied and was accepted. She is now an employment opportunity specialist working in the area of policy and guidance in Affirmative Action for the disabled, for women and minorities and for Vietnam era veterans. She was named one of ten Outstanding Handicapped Federal Employees of the Year in 1978, and one of 13 representatives of the federal work force selected to meet with President Carter.

Do you think 503 is actually working?

Sharon: “Yeah, I think it really is. And I think the kinds of experience both Jon and I had in our initial search for jobs just simply would not occur now. First of all, people would be scared to not hire you without good reason, and I think they’ve had some pretty big attitude changes themselves.”

Is there reverse discrimination? Do us gimps have certain advantages?

Sharon: “Hmm. (Laughs, pauses) Yes. Definitely.”

How about depression?

Jon: “I was probably pretty bitter. Still am, in a lot of ways.”

Sharon: “I just knew that it was like novocaine; it was going to wear off. See, I knew it wasn’t permanent, so I didn’t have anything to get all upset about.”

Jon: “You live with it. There it is, and you gotta beat it. If you want to do anything, you gotta beat it. But you don’t have to like it.”

And after 14 years of marriage, how’s it been?

Jon: “There’s been ups and there’s been downs.”

Sharon: “We’ve had sort of the normal kind of marriage with a crisis a couple of years ago when Jon and I separated for 16 months. What was unusual about it is the fact that we did get back together.”

Did the wheelchairs put additional stress on the marriage?

Sharon: “When it gets to the issue of marriage, the disabilities aren’t what’s important. It’s the people. It’s who and what you are.”

Jon: “A lot of it is just working around whatever situations come up. And the disability’s just one of the situations. There’s a lot of other ones. It certainly wasn’t the disability that caused the separation or getting back together.”

Sharon: “The emotional trauma and the pain of the marriage breakup and the separation was far, far, far worse than breaking my neck and anything that I’ve had to live through with this disability.”

I think that puts things in perspective.

So does this: Both Jon and Sharon were very active in the National Paraplegia Foundation, and now the National Spinal Cord Injury Foundation, of which Sharon is a director. Do you feel a need to put something back into the network of disabled people?

Sharon: “No longer do I really feel that there’s as great a need to plug something back into it. But don’t forget that we were around when there wasn’t the legislation that we have now—I mean, *somebody* had to be getting some things done.”

6.12.3 Beverly Nameche

Another car wreck, this time on a rainswept road to Boston: “I was waiting to see if my kids were alive, then I was going to decide whether I was going to live or die. And when I could hear, or was told, that they all were alive, then that was a very decisive point for me. Because I wouldn’t really have bothered. I think there’s quite a free choice there. To my right was a bright yellow light, really easy, really comfortable, and I could have just shifted over easily. Except on my left, I could hear my four year old crying. Now whether or not she was is questionable. But then I felt the tremendous need to pull to my left and to do the harder job.”

So it was that Beverly Nameche opted to raise her kids as a C6,7 quad. She doesn’t interpret the above events in a particularly metaphysical way, but more as a psychological state resulting from physical trauma. That was 1967.

Beverly was unlucky enough to begin her rehab at a general hospital in Massachusetts, and lucky enough to finish it at Stoke Mandeville in England. About the former she has very little to say, on the principle that if you don’t have something nice to say, etc.; on the latter she heaps praises.

“I spent eight weeks there as an outpatient and learned in eight weeks what I didn’t learn in about seven months in Massachusetts.” What she learned was to become completely independent. “It was excellent; very hard push. You’d arrive at 7:30 in the morning and have a tea break for a terrible tongue and semolina pudding or something, and if you could stomach it, you went on to the rest of the day. And left there at 5:30, green in the face because you’re so tired. They do not relent.

“I think rehab here in the States is really cream puff, at least the stuff I’ve seen. It’s about a two hour a day thing. Isn’t that ridiculous?”

It is ridiculous, and if that’s what you have now, you should know it. It is what most general hospitals offer. It is also worth noting that most American centers which are specifically in the business of treating SCI use Stoke Mandeville as a model for enlightened care. Most of them are hard push too.

Beverly continued her rehab by spending a year in Switzerland. “I thought that if I could go to another country and live and learn to drive a hand controlled car and bring up kids and deal with another language — all these unknowns—then I figured I could come back here and do anything I wanted to do.” What she wanted to do was to end her marriage, raise her children and move back into her old house in Gloucester, all of which she did.

The marriage had been rocky since before the accident, so there were no real surprises in its dissolution. She raised the ante on children by merging her mother-and-three-kids nucleus with a father-and-two-kids proton. Bringing them all up seemed like a pretty difficult undertaking, but nobody told her she couldn't, or she didn't listen if anybody did, so she went ahead and raised them. She encountered the most resistance over the house. Occupational therapists who looked at the house told her there was no way she could or should live in it, and she was so angered by their lack of imagination that she moved right in.

To be truthful, it doesn't look like wheelchair paradise. It's located about a block inland and upward from the sea. It's an old rambling structure of two or three stories, depending on which side you view it from, and clings to and around boulders and outcrops of bedrock. It's the sort of house some people worry about falling out of.

Improvements were made. An elevator was installed, not an Otis with a telephone, but a cheap industrial lift which works well. The driveway was paved up to the elevator door. A bathroom was added to the first floor, and a dining room and porch were converted to an open kitchen, living and dining area. The kitchen has counters at wheelchair height, a stove set directly into a butcher block, three or four knee holes for food preparation and dishwashing, a dishwasher, a side opening microwave oven and a grand view of Gloucester Harbor. She built a small sundeck, added vegetable and flower boxes, and gardens the steepest plot east of West Virginia. It's an extraordinary house in an extraordinary place.

Lest it be thought that Beverly's home is a monument to money, it's not. Completing it was an eight year project attributable more to tenacity than to dollars. It's a well loved house, and it's seen five children grow up. And it's seen some lean times.

"I've done some things for salvation, in order to keep the kids fed. I worked as a coordinator for three years on the Meals on Wheels program, which I started down here in Gloucester for elderly people, and I included handicapped people. That was just survival. I did it from the house and drove meals and got my kids to run them into houses and coordinated volunteers and ran the whole show."

Much of her work has been closer to her interests. She was involved in a study on personal care attendants done by Brandeis University, then spent two years running the peer counseling for Tufts Rehab Center's Independent Living

Training Program. She's just finished a four year term as a board member of the Boston Center for Independent Living and chairs one of the National Spinal Cord Injury Foundation's regional satellite programs.

"I left the Tufts job because my Medicaid was taken away. I'd given up my SSI because I was making a huge $85 a week. Then the Medicaid went, and I just couldn't afford to do that." Sound familiar?

So now she's moving toward sexual therapy. "I said Dammit, what's one of the big questions anybody deals with after you say Can I walk? or maybe before you say Can I walk? Why don't I pursue that if Mass Rehab will be so kind as to fund it?" Beverly's very open to new ideas, her own and those of others. "I take it one step at a time. What I do next year isn't what I'm going to do the year after."

Beverly feels that new injuries are likely to receive rather unimaginative advice about their options in lifestyle and career choice. I asked her if she once felt that the expectations of others were being forced upon her.

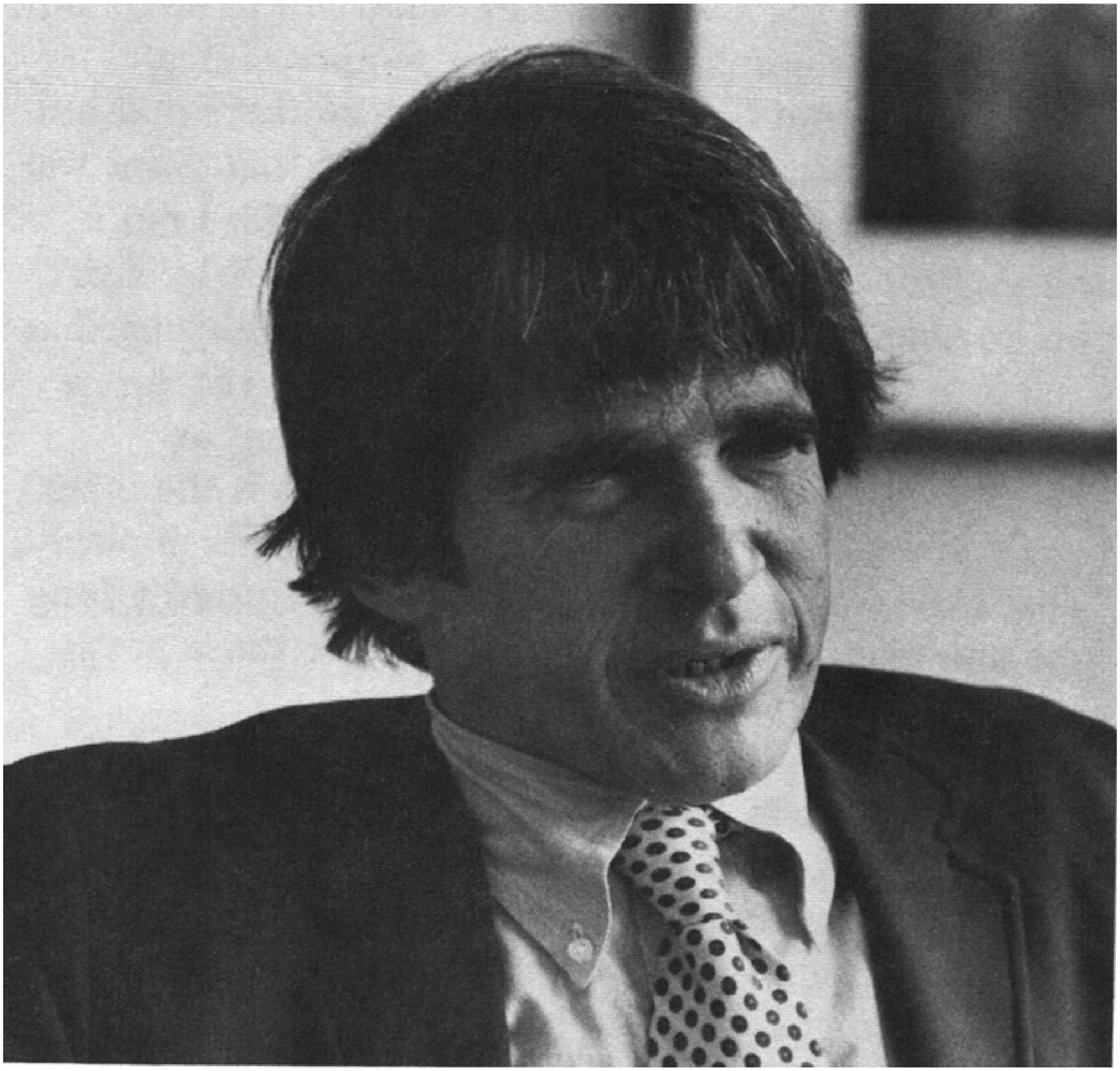
"No, I didn't. But I think that was partly because I was already married, was 33 years old and had kids. That's different from what happens to the young person who is immediately hit with—Oh You Must Go to School— because there is no other avenue that anyone is terribly creative about. But it takes time before a person knows. I think it takes some maturing, some aging with a disability, before you get to the point of, Well this is what *I'm* going to do because this is what meets my needs. What's different between that and an able bodied kid who's going off to college and decides he wants to take a year off?"

Hot tip department: "I think it's very important that people fill their lives as much as possible. I think sometimes right after injury, and right after leaving the hospital, you have to work at that. You have to think of things to do, you have to push yourself to get into things, to *get out*. I think I'm gregarious, but I have to push myself at times to get out and change my situation so that I meet new people and that I care about those people and they care about me. It makes my life fuller. But more important than that is that you have somebody to love and somebody who loves you."

Through hard times and good times, the years seem to have brought a lot of compassion into Beverly's life. How many years? She counts them mentally: "Why, it's been 12 years! Time flies when you're havin' fun, doesn't it?"

6.12.4 Bob Ludlow

Santa Cruz is a pleasant coastal village trying hard to outdo Carmel in the charm and quaintness departments. Bob's office is in an old, re-done section of the town, not pretentious, but carefully planned funk. The sign says Ludlow, Thompson, Fitzwater and Bolles, Attorneys at Law. Bob himself is friendly and athletic looking, nattily dressed in blue blazer, polka dot tie and button-down shirt. One of his colleagues looked in to ask why he's so duded up today — it's for his upcoming lunch appointment.



He drives a Mercedes, although he admits that compared to his old Chevy II, it's a poor wheelchair car. Bucket seats. He has a home in the hills above town; very rural. Horse country. His wife, Sherrel, likes dressage. Their two kids like everything. It's the American Dream. The good life.

Bob was 13 when he broke his neck on a water slide. C5,6. 1952. Since Santa Cruz had no rehabilitation facilities— had probably never seen a surviving quad before— Bob stayed home with his parents for two years, then shuttled between a general hospital and a rehab center in San Francisco for another year.

"The state of the art then was not anything like what it is now. They approach it a lot differently now. They lower the expectation level at the very beginning. They say, You have a devastating injury, you're going to continue to be this way, you better get started doing *something*. In the old days, they'd say, Wait and see what'll happen. They'd foster that feeling, then you'd have that extreme depression when you found out nothing was going to happen.

"Around 16 or so, I came back home after the rehab. My dad came in and said, Hey, a bunch of the kids are up at the pool and they want you to come out. I said, I'm not going to. I threw a temper tantrum, God, I cried, and he forced me to go up there and put me in the center of it. And my choice at that point was, continue to act like a punk or get into it. So I did it, and everyone said, Why don't you do this, Why don't you do that? And it became such a hassle refusing that I fell into it, I started flowing with it. And you know yourself, you don't have any problem dating or anything else, because if you can adjust to it the other people around you can adjust to it." He grins impishly. "That's the way I handle it now, that I adjusted a long time ago and now I just have to wait for those people around me to."

The rest of it seems relatively simple. "I got off (on?) my ass when I was 16 or 17, went to junior college for two years, went to Stanford (on a scholarship) and then I went to Hastings Law School so I'd have three more years to make up my mind what I wanted to do. I decided to become a lawyer, probably, after I'd gone to law school. I graduated in 1964, was with a law firm here in Santa Cruz for a year and a half and then I went on my own."

He's been on his own, as an attorney, for 16 years. He and Sherrel were married 15 years ago and have adopted two children. Justine, now 10, is named from Lawrence Durrell's *Alexandria Quartet*. Tom, 12, more commonly known as Tigger, is from *Winnie the Pooh*, a classic of equal stature. The Saint Bernard is Gudrun, from *Women in Love*, and another less visible dog is Pooh Bear, another tribute to Milne.

Back in the office, I thought of *George Hohmann* and his epic struggle to adopt kids, and asked Bob if they had any trouble with adoption proceedings. None. He couldn't believe that anyone ever had. He admits that his attorney's manipulative skills, "people management" being the euphemism preferred by the trade, may have helped with the adoption board. "Basically, life is just dealing with people anyway."

Bob specializes in criminal cases, personal injury, business and labor arbitration. Is the chair a restraint? Nope. He doesn't believe the old saw that a disabled attorney prejudices his client's case. The court rooms are accessible, and in Santa Cruz, even the jury box and bench have been made accessible.

He does, however, have a complaint. There were two young quads who once came to him for advice. They were both bright, so he urged them both to go into law. They did. Trouble is, they both hung up shingles in Santa Cruz. "Both of them came and practiced in my town. It's no longer a unique experience for anyone in a wheelchair to be a lawyer." His rueful expression is not for real— Bob is a ham.

He has built a credo, mainly derived from Dante's *Divine Comedy*: "The worst place to be is limbo. Not purgatory or paradise, but the place where you don't make choices. It's extremely important that people not put themselves in limbo, because choices don't hurt. There is no such thing as a mistake or a failure when you make a choice. You learn each time you affirmatively make a decision. I guess that's the first thing you have to learn—that you have to make choices."

And later on? "You have to re-establish your independence at some point in your life, because you get to the point—I don't know about paras, but for quads — that it's so easy to have someone else do it. Timewise. So you slip into that. Now I'm trying to get back away from that. I'm getting into doing more things myself again.

"Part of what I'm doing now is, I've decided to go out and live on my own for a number of months just to see if I can do it. It's sort of hard to explain to my wife —it's nothing personal—but that's what I'm doing. And one thing I've found is, it's not that difficult."

Finding an attendant was a momentary concern. "You use someone for half an hour in the morning and half an hour at night. I think that subconsciously, going out and placing such reliance on someone was something that bothered me a great deal. But that anxiety you suffer in making that choice doesn't really exist because once you do it you find out it doesn't mean that much. The anxiety's all over with. All you do is ask someone. The fears you have are not genuine. What's really strange is that it takes only a couple of hours for someone in my situation to make changes occur that'll make their whole life different."

Now we're back at home with the kids and dogs. Bob's here too, running things while Sherrel's on a trip to Mexico. Do the kids help with the work? "Yeah. I made a deal with them where we're supposed to share it equally, so it isn't a matter of just ordering them to do it at all. The kids' idea of equal is different from mine." Justine displays a chart outlining everyone's chores: kids bring up wood, unload the dishwasher and clear the table. Dad gets to cook and wash dishes.

It's not all one-sided. "The things I need done, the kids are really helpful about. Like in the evenings, when no one's around, the kids'll throw me into bed and make it a project. You sort of like that don't you?"

Justine, in a fit of giggles: "I know. It's fun. Singing around, it's real funny. I like it. I like taking showers with you." Justine is half kitten, half ham like Bob. She clings to him as he brushes her hair. "When I get dressed in the morning, it's completely open. I don't understand why people have this ethic —even if they're not in wheelchairs —about getting dressed and taking showers and all that stuff, because these are all part of life with us."

The place becomes a soundman's nightmare. Justine is clunking around the wood deck on rollerskates and Tom is dribbling his basketball while doing one-handed wheelies in Bob's spare chair. What's Tom think about his dad being in a chair? "He's still the same." What's the basketball team your dad's going to coach? "The Santa Cruz Roller Coasters. I'm gonna probably be assistant coach." Are you good enough for that? "Yeah, I know a lot. I can show you, shootin' from a wheelchair." He did. He also said he'd show me how he could go up two stairs in a wheelchair. I didn't believe it until I saw it, when the method became clear. The two steps were separated by 30 feet of sidewalk.

Bob compares a SCI winner to Pangloss, in Voltaire's *Candide*: "You're foolish enough to think that it's the best of all possible worlds, when it isn't. It takes that kind of resiliency, a lack of cynicism, to the point where you can like people, you can like events, even if an objective viewpoint might say that the person shouldn't like that situation. You know, it's no fun being in a wheelchair, but it's like the guy who goes in the service and he's stationed in Paris, and he hates the service so bad he doesn't like Paris."

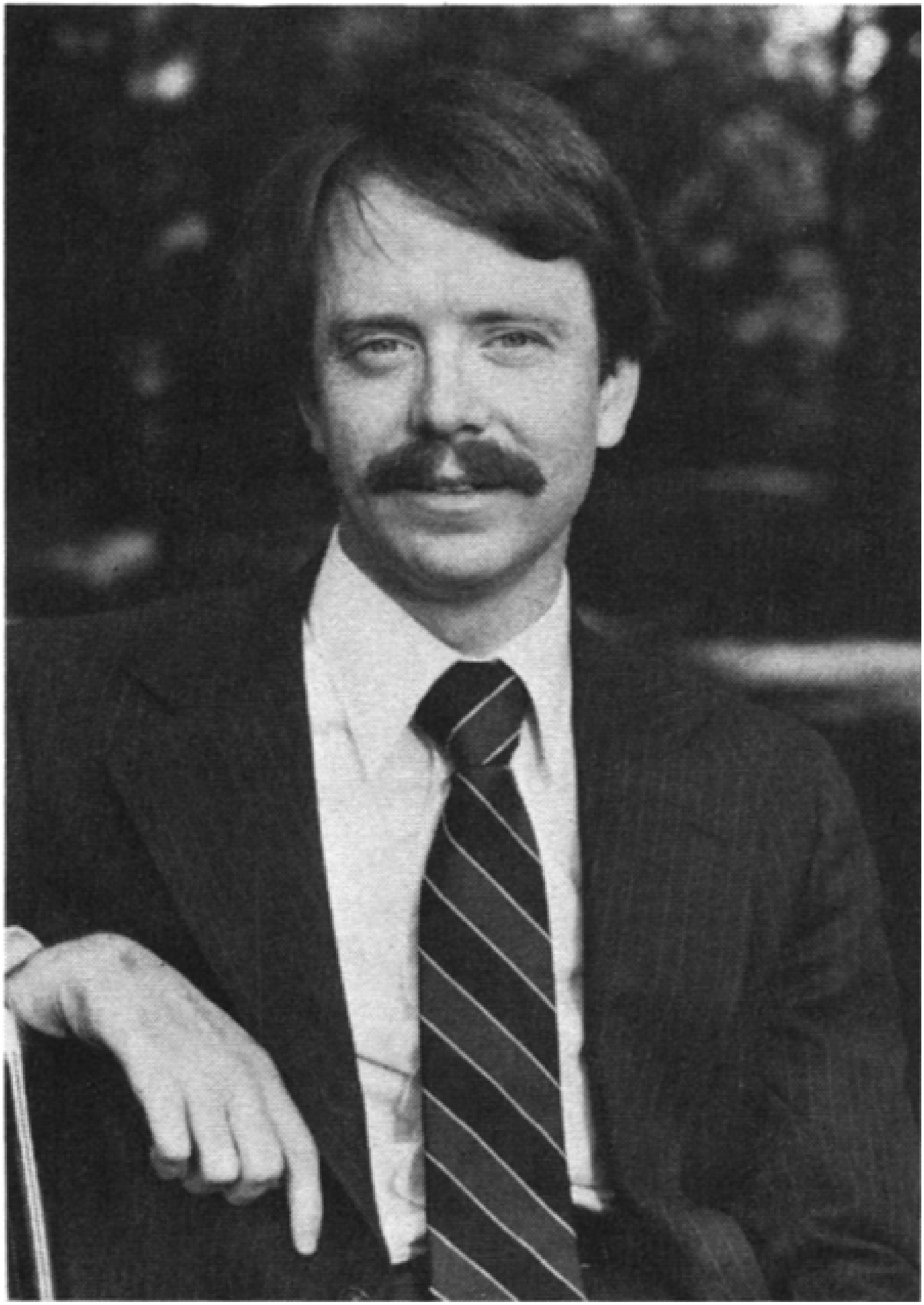
Final admonition: "Take a chance. Because they really aren't chances. It's a chance for success. There's no chance for losing by taking a chance. There's no way you can lose. If I were to talk to anyone who was thinking of a career, something to do, I'd say Do it. Just do it."

6.12.5 Robert Heist

This is not Rob's first (or second or third) appearance in print. He's the world's easiest interview, and people capitalize on that. Young, articulate, likable, well placed in the business world and highly visible in his community, he'd be called an overachiever without his injury. As it happens, he's a C5,6 quadriplegic. Rob so impressed Dr. Howard Rusk that his story serves as a forward to Rusk's autobiography, *A World to Care For*.

It was a water skiing accident in the summer of 1966, just after he'd gotten his business degree from Tufts University. He was 21, and had an appointment to report to Officer's Candidate School and thence to Vietnam. He broke his neck and his plans changed.

Rehab started at the Boston University Medical Center, four and a half months of it, followed by the same length of time at the New York (or University) Hospital Institute of Rehabilitation Medicine, more commonly known as the Rusk Institute. There he reviewed his vocational options, decided on the insurance industry and returned to the Boston area to make his way in the world of business. After applying to several large insurance companies, he finally settled on John Hancock and became a management trainee at $100 a week.



“I started the year after I got hurt and only three months after I was out of the hospital, so I really didn’t know what I was going to be able to do. I had the degree, but I didn’t know whether I’d be able to perform on the job. And they didn’t know either. So we figured we’d do this for a year. At the end of a year it looked good to both of us—I liked them and they liked me. So I’ve gone up through the ranks, done a lot of systems work and now I’m assistant manager of a unit of 72 people. In August I’m getting promoted to a systems job, as a systems analyst in the new business department, so things are working out well. Jobwise, it’s been terrific. It’s been a good 13 years.”

So much for a business career. Everything Rob does seems to be like that, done directly and efficiently, with no false starts. He needed to drive to work, so he bought a car and now drives 18 miles each way, winter and summer, between suburban Wayland and downtown Boston. He wanted to become completely independent so he worked at it for two or three years until he succeeded.

“To be able to do all the bathroom stuff, all the bowel and bladder routine, the dressing, the general food preparation, driving —it’s really important. I’m not sure I’d want to live alone, in fact I’m sure I would not want to live alone, because it’s a lot of work. I also know that if I had to, I could. And I have done it for extended periods of time.”

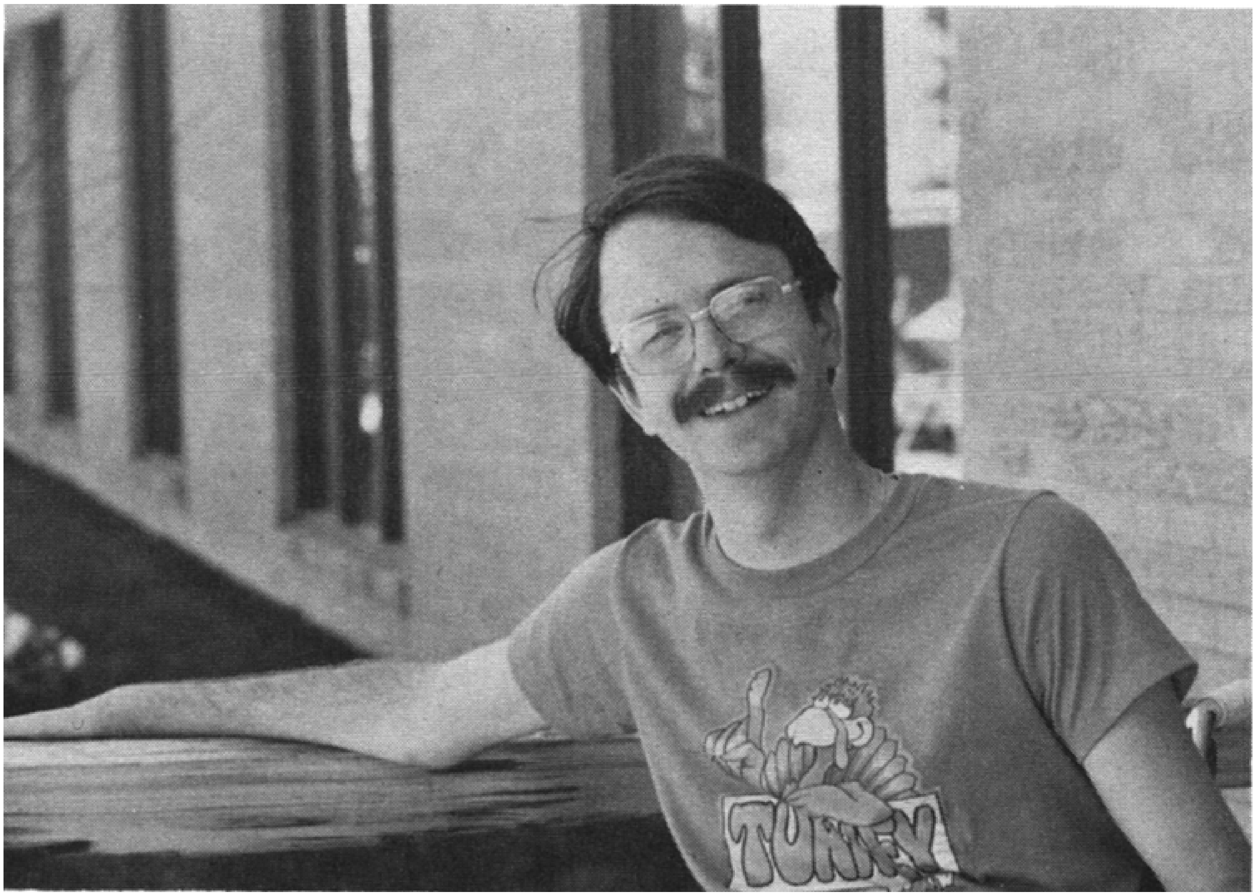
He became active in the New England Spinal Cord Injury Foundation, one of the two parent organizations now merged in NSCIF: “I’ve done a lot of work with the New England group, and a lot of that has been speaking to groups about SCI, about attitudinal barriers, people with disabilities, rehabilitation, vocational stuff, architectural barriers, the whole thing.”

For example, Rob feels that attitudinal barriers are largely a matter of people seeing the wheelchair more than the person who occupies it. People are awkward because they’re unsure of themselves.

“I try to get right out in the middle of the group, so they’re all around me, and then I say, Now this is maybe the first opportunity for you to look at somebody in a wheelchair and really stare and really get a good look, because usually when they’re kids their mothers tell them, Ooh, Bobby, don’t look. So I get in front of a group and give them a chance to look. I know that first, they’re looking at the wheelchair, but I also know that they’re looking at the person in the wheelchair. So it gives them an opportunity to sort of personalize themselves with someone who has a disability. It’s a good ice breaker.”

Recreation: Bowling in the winter and boating in the summer. He keeps his 17 foot outboard on Lake Winnepesaukee in New Hampshire. Although he needs help transferring from the dock, he drives the boat from a locked down wheelchair.

“The nice part about having the boat is that on summer days I can be with my friends all day long, and instead of sitting by the side of a tennis court watching everybody have fun, I’m right in the middle of everything. In fact, I’m supplying the fun. The fun is something that I’ve brought along, and people can swim off the boat, they can water ski, they can sleep, they can drink, they can relax, they can fish —there’s any number of things people can do from a boat and if a quad’s in the middle of all that, it’s terrific.”



Friends: “Relationships with friends are very important to everyone, but I think that people with disabilities tend to withdraw frequently from relationships that they’ve had or potentially can have, because they might feel inadequate or like they just don’t have anything to offer to the relationship. And that’s something that everyone with a disability has to overcome. Once they realize that there is a barrier there, but that there is something they can do about it, I think that’s the first step. And then they have to go about the business of deciding in their own minds that they do have something to offer and that given the disability and given the difficulties that are involved with the wheelchair and the things they can’t do, that they’ve got to key on the things they can do and the things that they can give to other people.”

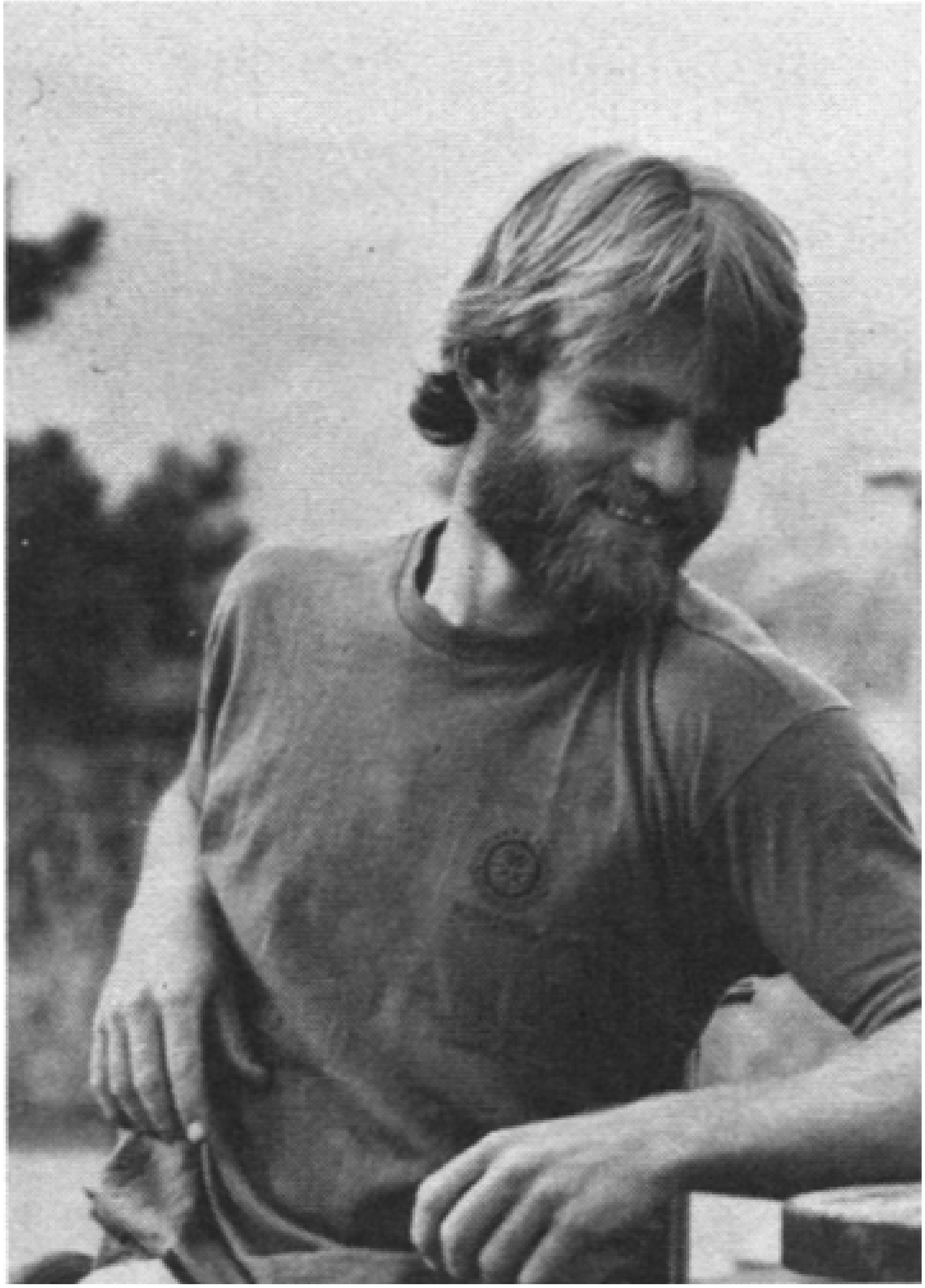
And a final admonition: “A lot of newly injured people see films of paras and quads having a good time, going out in their own boats, bowling, doing wheelchair sports, having good relationships, and it’s almost like the pitch is *Get a SCI and start enjoying life*. That’s not where it’s at. It’s not that way at all. This all looks like a lot of fun, but it’s a substitute for what we all knew and enjoyed before. The notion that the SCI doesn’t exist is wrong. It is there, it is present, it’s something that somebody with a cord injury has to adapt to and adjust to and live with. And that’s how it is. It’s tough, but once you’ve sunk down low enough, then you can start to climb back out. And when you start to realize that you do have something to offer, then you realize that the fun and games are in fact enjoyable and rewarding.”

6.12.6 John Galland

“I had a friend come to me in the hospital and he said, Look, I just came in to ask you, do you want the tablet? And this guy is real physical, and we used to do a lot of stuff together, and I looked at him and said, God, you almost understand, don’t you? It was really a very touching moment in terms of the empathy he had for the whole helpless condition.”

That’s about the way John was thinking when we first met in 1971. He had some strong scruples about doing himself in, but rather wished the accident had taken care of it for him. He acted wired —he couldn’t seem to articulate a sentence without popping a wheelie at the same time. Just another hyperactive kid from Texas.

I ran into him at Craig a couple of years later, and we recorded his thoughts on tape. The bitterness was still there, but he had become very analytical about his condition. In fact, he was so intelligently eloquent about why being paralyzed is less fun than the circus that his voice ended up as a major part of the soundtrack to *Changes*, the film I was working on at the time. Yet his whole psyche seemed somehow brittle, as if one part of his brain didn’t quite believe what another part was telling him. He was fighting something, and the fight was drawing down his energy.



Now, in 1979, we're talking at my house. He exudes so much physical and mental health, I want to excuse myself to go do push-ups. He's an extremely well person.

Gurdjieff, and others, have described energy as manifesting itself in three ways: physical, intellectual and emotional. While a few of us are wondrously balanced in our manifestations, most of us express ourselves most fully in only one of the three ways. John's way is physical. That's not to say that he's intellectually or emotionally deficient, but that whatever he *is* is best expressed physically. And with John, it's not just a need to be physically active, since a wheelchair marathon would satisfy that need, but it's a need for *risk*. He's a risk person. So am I, which explains why it took me so long to recognize it in John. Most of us aren't. Risk is what makes John whole. Risk is what *has* made him whole.

John was always a righteous athlete. Whatever he did, he did as hard as he could. He tried to expand his limits in everything. In 1971, he actually succeeded in skiing through a tree, rather well above snow level, but it left him a

T10,11 para. It was three days after his twentieth birthday.

After two weeks in Grand Junction, Colorado, and six months in Dallas, “I got up in a chair and was just freakin’ out, goin’ Boy, if this is the life afterward, give me the gun. I want it.”

“I said, Look something’s gotta happen. So they sent me up to Craig for a month and a half. Craig allows you your physical limits — whatever you want to do, that’s cool. And it’s really unique. Because I was goin’ down stairs in my chair, sittin’ on the floor and fallin’ over, and nobody minded. It wasn’t as if I was made of eggshells. And so I came away sayin’ *Yeah! It’s gonna be alright*.”

That was when I first met John, and I reminded him that he still wasn’t all that keen on the joys of paralysis.

“Right. It took about five years, and then the enjoyment began to return. I can go out and crash around in the woods and take a certain pleasure in doing things. I guess I lost the comparative reality.”

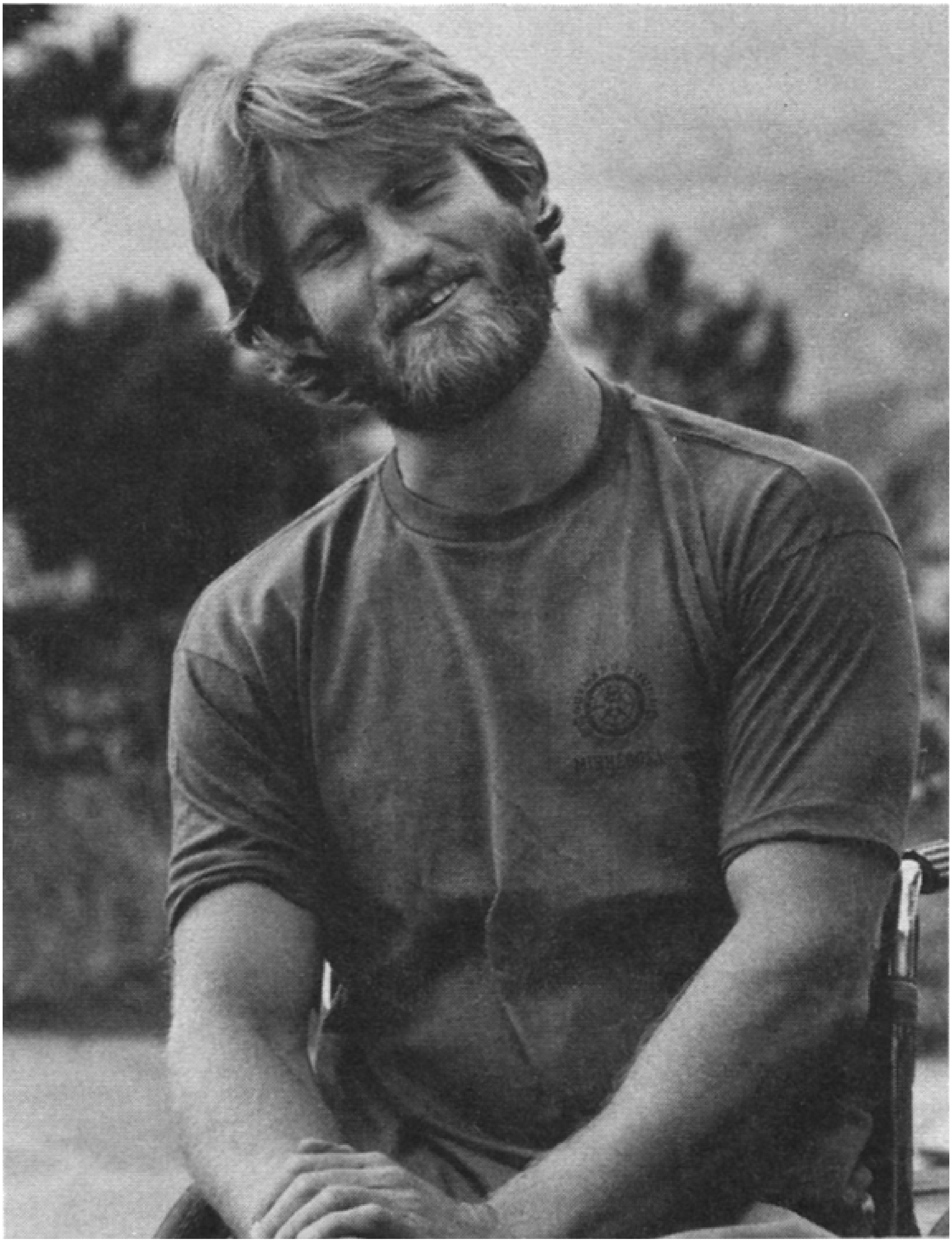
Comparative reality?

“Just the whole thing of always comparing yourself to what *was*, what you *could* do. Jesus, how futile that is. And I had to get rid of it. And the way I got rid of it was through crashing around.” John showed me what he meant by crashing around —he wheelied down the seven steps of my front yard for starters, did it again and splattered on the driveway, but was undamaged and undismayed —“You gotta learn how to fall” —then zipped down the steepest part of the hilltop I live on just for the hell of it. He takes wheelchairs where angels, able bodies and off-roaders fear to tread. “That was a real big attitudinal change, because it’s just suicide to keep comparing yourself to history. What does that have to do with anything now? You can bang your head against that wall only so long.

“After five years of hanging out and being high all the time, trying to run away from it, I finally got to the place where I was convinced I wasn’t all that fragile. You have to figure out what makes the difference for you. For me, the physical risk, getting out in the woods by myself — Like I said, I lost my comparative reality.”

More about risk. Since I expended most of my pre-accident energy on climbing mountains — difficult ones, sometimes previously unclimbed, often at ridiculous altitudes and latitudes —I was constantly asked about risk. Why should risk appeal? Isn’t risk the opposite of life? Why jeopardize what can’t be replaced? Well, I’m a veritable fount of answers, both corny and profound. But all you really need to know is that risk enhances the life experience for some of us. John is equally unwilling to get specific: “I can’t tell somebody with righteous fervor that this is the way it should be, because everybody’s a different case. And there’s nothing that you know for sure about anybody. That’s another thing that being in a chair has taught me.”

But for him: “In a physical sense, I’m much more whole, because I consider all the possibilities that I have and don’t limit myself. When I was a walker, I didn’t want to do a lot of things because they weren’t chic enough or they didn’t have enough mystique or they weren’t tough enough. And nowadays I’m not that way. In a sort of psychic or mental sense, I’m much more whole because I’ve got so much more perspective. One thing the chair has brought me is perspective.” Maybe you’re maturing? “Heaven forbid. No, I feel so much better now because I’m not a bitter, petulant little boy like I used to be.”



So, although John has not picked up his bed and walked, he has wheeled far into the wilderness. But what does he do in real life? He's a professional student.

“I enjoy learning. I’d find a good teacher and study economics for two years. And I studied political theory for two years. I was a pre-med for a year and a pre-law for a year. So now I realize I’ve got 140 hours and no degree over six years.” Do they give a degree in becoming a renaissance man? “No, but that’s what I’d be going for.”

His present aspiration is to get a degree in psychology, because Texas needs help. He wants to form a private resource and service corporation to influence attitudes and legislation. “There’s a lot of folks in chairs in Texas who are not at all *out*. A lot of homebodies in wheelchairs, because there is so little information and a great suspicion of social services. A hell of a suspicion.” Why is that? “I think it’s because of the war. Not World War One or anything like that, but the *Civil* War.”

In the meantime: “I do some silver smithing, I live a simple lifestyle, and I eat lots of beans and rice and tortillas.”

Does he have a hot tip? Yep. Two of ’em.

“Plant your corn early. Sleep Dancer in the fourth.”

6.13 Op Ed II

6.13.1 Killing the Cripple

We are late-blooming lemmings. We wage war upon ourselves. Listen:

> “There is no need to sally forth, for it remains true that those things which make us human are, curiously enough, always close at hand. Resolve, then, that on this very ground, with small flags waving, and tiny blasts of tinny trumpets, we have met the enemy and not only may he be ours, he may be us.”
>
> —Walt Kelly

The enemy is us and is running on empty. The enemy is vulnerable and should be iced right now.

Everyone has hunch-shouldered days. I sometimes keep a low profile, thereby avoiding engagement of any kind, or perhaps I’m stupidly vulgar or vicious to other people. That’s pretty human. But it’s easy to use the fact of paralysis as a fictitious focus for our discontent …

Conversations

- To a stranger: Why are you looking at me that way? You’re not?
- At a standup cocktail party, balancing a martini, admiring all the belt buckles at eye level and trying to make progress: Would you please let me through? No, you’re parked on my foot. That’s just before the hostess’s skirt gets tangled in your spokes and your drink spills in your lap.
- As you’re jaywheeling across a busy street, a gust of wind blows several packages off your lap and down the street. Passerby: Can I help? NO! Can’t you see I’m uptight?
- In a crowded elevator, an older woman has spotted you as a mark for a nice conversation, and you have spotted her and know beyond all doubt that she’s about to impart this information: I have a very dear friend who is in a wheelchair. RI-IGH-IGHT. It’s not nice to be sarcastic.
- At the bank: Sir, is your wheelchair leaking? No comment. Oh, it’s your shoe! Didn’t hear that.
- Five or six wheelers are in the basement catacombs of a hospital. There seems to be an uncalled-for amount of giggling, and conversation is punctuated by sharp intakes of breath, long pauses and explosive exhalations: Wow (intake, long pause), do you realize we’re all (exhale) in *wheelchairs*? Group breaks up in inexplicable laughter.

This last, the *reductio ad absurdum* approach, serves well when you’re loose enough. What could be more lovably ludicrous than a man in a wheelchair chasing a hound in heat? How do two wheelers travel in one car? Simple: driver transfers first, passenger places driver’s chair in trunk, transfers himself, loads his chair behind the front seat, then realizes he left the trunk open. How do you empty a leg bag on an airplane? Use the barf bag? Refill your Cutty Sark Minis? It’s not bad to play kick the cripple as long as you’re doing your own kicking.

I have never felt despised for being in a wheelchair. I have felt pitied; I have despised myself. The first is the other person's problem and the second is mine.

I've had glorious days, days when everyone and everything I encounter dances to some tune I know well. On those days, confidence and good cheer flow out of me and infect total strangers. Little children leap spontaneously into my lap and their mothers don't mind. Rainbows spring from manhole covers and the world is truly wondrous.

And on some days, the wheelchair becomes a rolling ghetto—a chrome cage that blocks communication absolutely. Period. Don't bother me. I'm crippled today.

It seems possible that my body, my wheelchair and my social and physical environments are relative constants which cannot account for these changes. Damn ol' elusive cripple —now you see him, now you don't.

Some wheelers have dealt with their cripples as if they'd had a desperate tussle with the devil. One struggle and it's done. The rest of us have to deal with him every day. It's sort of a nuisance, but it's good practice for making things good.

And when it's good, it's really good. These are the days when the cripple just lays over and dies. R.I.P. cripple. Bug off, cripple.

Years ago, Polly and I once cavorted on Hollywood Boulevard. We encountered a man with a wolf's head, another with a brassiere over his ears and hundreds of lesser artists who flaunted their most bizarre fantasies on this warm weekend night. Exhilarated, caught up in the general freak-flow, we zipped through intersections, jumped curbs with incredible coordination and used the other actors (i.e., everyone) as slalom poles. At last we were accosted by a couple with radioactive brillo hair. Where did you get your act? they asked. That wheelchair, that curb routine? I pointed out the magic store east of Las Palmas, and they were off to buy next weekend's fantasy.

The cripple is dead.
Long live the cripple.

6.13.2 Heroes

If you don't like trippy metaphysics, obscure speculation, philosophical pretensions and mythology, or if you feel that molehills are too often intellectualized into mountains, skip this section. There will be no quiz.

Here's the thesis: Your injury is an epic thing. *It reeks of mythic heroism*. Wanna be a hero?

The fact is, you have little choice, but you might as well understand the process enough to do a little sightseeing along the way. Can't tell the players without a program.

The general idea was first made apparent to me through a sampling of Carl Jung's work, then very concretely by Joseph Campbell's THE HERO WITH A THOUSAND FACES.* What follows is entirely informed by and indebted to these two men. The shortcomings are mine alone.

Psychologists and anthropologists have long talked about archetypes, the basic unconscious touchstones of the collective human psyche. These archetypes are real in every sense, since they are manifested with maddening consistency in the dreams, delusions, deleria, fantasies, fairy tales, religions and myths of virtually every culture both past and present. Because it is not the specific content of these manifestations which is consistent so much as basic form and repeated motifs, Campbell has used the word *Monomyth* to represent the whole grab bag. In examining the Monomyth, he finds a constantly emergent pattern which he calls the *Hero's Path*. What's more, he holds that if you can bring an understanding of this Path to a conscious level (since it's already in the unconscious levels), then you can follow the path in your own mundane life, resolve all difficulties and live happily ever after in the knowledge that Osiris, Gilgamesh, Jonah and Theseus all were heros in spite of zits, warts and inferiority complexes.

*Campbell, Joseph, *The Hero With a Thousand Faces*, Meridian Books, The World Publishing Co., Cleveland, 1949.

I really don't want to be flip about Campbell's work. The stages in the Hero's Path are not fairy tales, even though they may be found in fairy tales. There is something real and universal here, and if we can just find ourselves within the Monomyth, a lot of things make sense. Things like Why? Why me? and What next? all find a context. If we can see the context, recognizing the stages of the Path as we encounter them, then all the crummy details become pretty insignificant because they're only minor variables in a universal pageant.

The first stage is Departure, an abrupt break in life as it was known. A significant event takes place (SCI might qualify), or in Campbell's words, "The familiar life horizon has been outgrown; the old concepts, ideals and emotional patterns no longer fit; the time for a passing of a threshold is at hand."

Well congratulations and welcome, here you are already across the threshold and on your way. Campbell suggests that there is usually a refusal of the call to the Path, good news to shrinks who insist that denial is a prerequisite for successful rehabilitation: "The subject loses the power of significant affirmative action and becomes a victim to be saved. His flowering world becomes a wasteland of dry stones and his life feels meaningless." He's anxious, dissatisfied and feeling just as many of us have after our injuries.

The second stage of the cycle is Initiation, which can be seen as a ritual designed to allow the individual to die to the past in order to be reborn to the future. Adolescent circumcision, for example, along with its obvious Oedipal connotations, cuts the male child's dependence upon his mother and invests him as a participating adult. Novitiates may wed Jesus Christ as consecration of a new life role. More generally, there is a radical severance from the attitudes, attachments and life patterns of the stage being left behind, usually accomplished by a series of trials set in the hero's way. Odysseus had his sirens and moving rocks. The Twin Heroes of the Navajo had their clashing rocks, slashing reeds, tearing cactus and boiling sands. You have your involuntaries and blown externals, your spasticity, dysreflexia and decubiti. Sort of a filthy crew, to be sure, but heroic obstacles nonetheless.

The Initiation is concluded by an atonement, or at-one-ment. To take a theistic example, if God created man in His image, atonement consists of man recovering his Godhead, his universality. This is the rebirth. In more moderate terms, he is no longer a lost and lonely ego playing bumper cars with alien forces — he assumes and is assimilated by his real condition, which is humanity:

> "In his life-forms, the individual is necessarily only a fraction and distortion of the total image of man. He is limited either as male or female; at any given period of his life he is again limited as child, youth, mature adult or ancient; furthermore, in his life-role he is necessarily specialized as craftsman, tradesman, servant or thief, priest, leader, wife, nun or harlot; he cannot be all. Hence the totality —the fullness of man—is not in the separate member, but in the body of the society as a whole; the individual can only be an organ… If he presumes to cut himself off, either in deed or in thought and feeling, he only breaks connection with the source of his existence."

The final act is the Return from the psychological equivalent of sidereal space, a reintegration with the world that was originally left behind. This life-enhancing act has special significance for all humanity because the hero's passage has so faithfully enacted the Monomyth, so brightly illuminated the deepest wellsprings of our beliefs and existence.

So having died to a portion of the past, having passed through the fires of initiation and prevailed over all obstacles, the hero is ready to make visible his rebirth as a more complete being by returning to the world. Often, there is an initial refusal to return; ask any rehab counselor. The problem of the return is to knit together the two worlds; the one departed from and returned to, and the other world encountered during the journey. That, hero, is your task. Follow the Path.

We are the twice-born.

We represent to humanity its greatest fears of catastrophe and its greatest hopes of transcendence. We have embarked upon the Hero's Path and we have no choice. Willy nilly, we will all become moral hygiene teachers.

To others, our transcendence is the proof of our heroic energy and direction. To ourselves, our energy and direction derive from the need to transcend because *there's no other way to survive.*

If you got nothing to transcend, man, and woman, you're nowhere.

6.14 Lives VI

6.14.1 Tom Deniston

There's a certain irony in his accident. He'd been a pilot in Vietnam for two years, put in 2,000 hours of combat time, had lost two airplanes and had walked away from both of them without a scratch. Then, one day, while he was leaning on a porch railing jawing with some friends, the railing collapsed and he fell 12 feet. He's a C5,6 and doesn't think highly of porches prefabricated by the lowest bidder. That was 1969, a week before his thirty-first birthday.

In 1969, Tom had a college education, a passion for flying, a wife and three boys. He had decided early on what he wanted from his occupation: "I wanted a job I could enjoy and I wanted to be able to help other people. And from that came the idea that I should go into the Air Force." And from that came eight or nine expense-paid trips around the world, a broken neck, a rehabilitation at Fitzsimmons in Denver followed by more at the Memphis VA Hospital, a job for two years with a large envelope company and the realization that he has a knack for changing people around to his point of view. That led him into advocacy work for the disabled, which brought him to the attention of the Paralyzed Veterans of America, whose vice-president he soon became. After two elective terms with PVA, he moved to Albuquerque to attend graduate school at the University of New Mexico, but dropped higher education in a flash when PVA decided to set up a pilot advocacy program in Albuquerque. Tom's now Advocacy Director for the Southwest Region of PVA, about which more later.

Tom's first job at the envelope company satisfied one of his major concerns, which was to prove to himself that he could rejoin the work force. He had two other burning concerns: flying and sex, in that order.

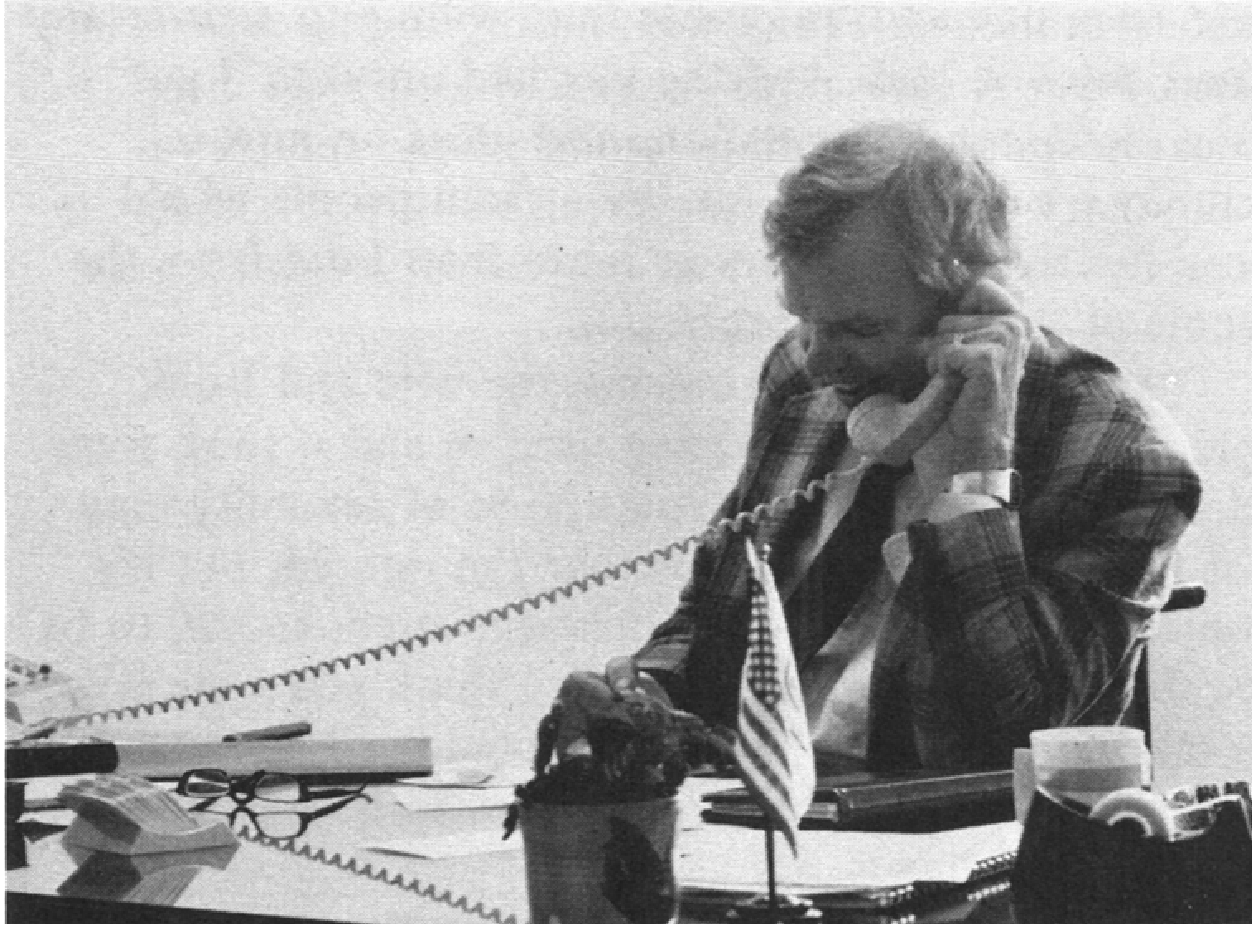
"My neurosurgeon came wandering in, and I've got a question. I want to know when am I gonna get back to the cockpit? When can I go flying again? And his comment to me was something along the line of, Oh, you broke your neck. You're gonna be paralyzed from the shoulders down. Don't worry about it. You can go home and eat and sleep and watch TV and talk and enjoy life and collect your benefits. Tom feels that this attitude represented, say, a limited outlook.

Yet *nobody* at the hospitals could tell him anything about flying, until one day an old injury told him that you can fly an airplane with hand controls. "Well that solved *that* problem."

Then, he asked his urologist about sexual function, who told him "It's a little too early to tell." He persisted in asking his nasty little question, and got shunted from referral doctor to urologist to social worker to psychologist and back, and got no answers.

"I got lucky. In the Memphis VA, the medical doctor in charge of the outpatient clinic was a quadriplegic himself. He'd not only worked in SCI, but he'd been one and was more than willing to answer any questions you had. And the guy had answers. I got more solutions — suggestions and ideas on how to remedy a questionable sex life—from people who'd been injured for 10 years or more than I did from the whole of the medical profession.

"We had a lot of problems, the wife and I did, initially. It took some getting used to and it took some changes of attitudes. My conception of sexuality may not be totally reversed, now that I'm injured, but it's considerably different. The male ego used, to me, to be the thing that everyone seemed to think you were trying to take care of. And that's not where it all is. Sexuality has to be a sharing thing, and it has to be a pair of egos satisfied simultaneously.



“A young fellow was injured recently, and it just hurt so badly to see him lying there saying, *I’m half a man now. That’s it. That ruins it. I am no more a person*. And that’s just so *terribly* wrong! If you can be the sharing, concerned, empathetic individual, the two of you work out an arrangement where both of you are not only comfortable, but satisfied and pleased with the whole situation. You’ve reinforced your partner who in turn is gonna be more anxious to reinforce you, which, in my estimation, makes you a better person than the macho bull that you were to begin with.”

About his kids, now teenagers and young adults: “You can go to movies together, you can go to ball games together, you can do a lot of things and still get the comradeship, the father-son relationship, without having to go out and make a major production of climbing the Matterhorn with your son at your side.”

A few sidelines — He’s active in Handicapped Scouting, lectures to medical students about disability and sexual function, does a Sunday radio talk show, bowls regularly and travels a lot, both on the job and off.

He credits his unusually good arm and hand function —“I’d arm wrestle anybody for a beer in any bar in town” —to his determination to get strong enough to throw the neurosurgeon of limited outlook out of the armed forces. As a matter of fact, he attributes *everything* good to determination, and to see Tom Deniston’s determination in action, the thing to do is roll into the Southwest Regional Office of PVA.

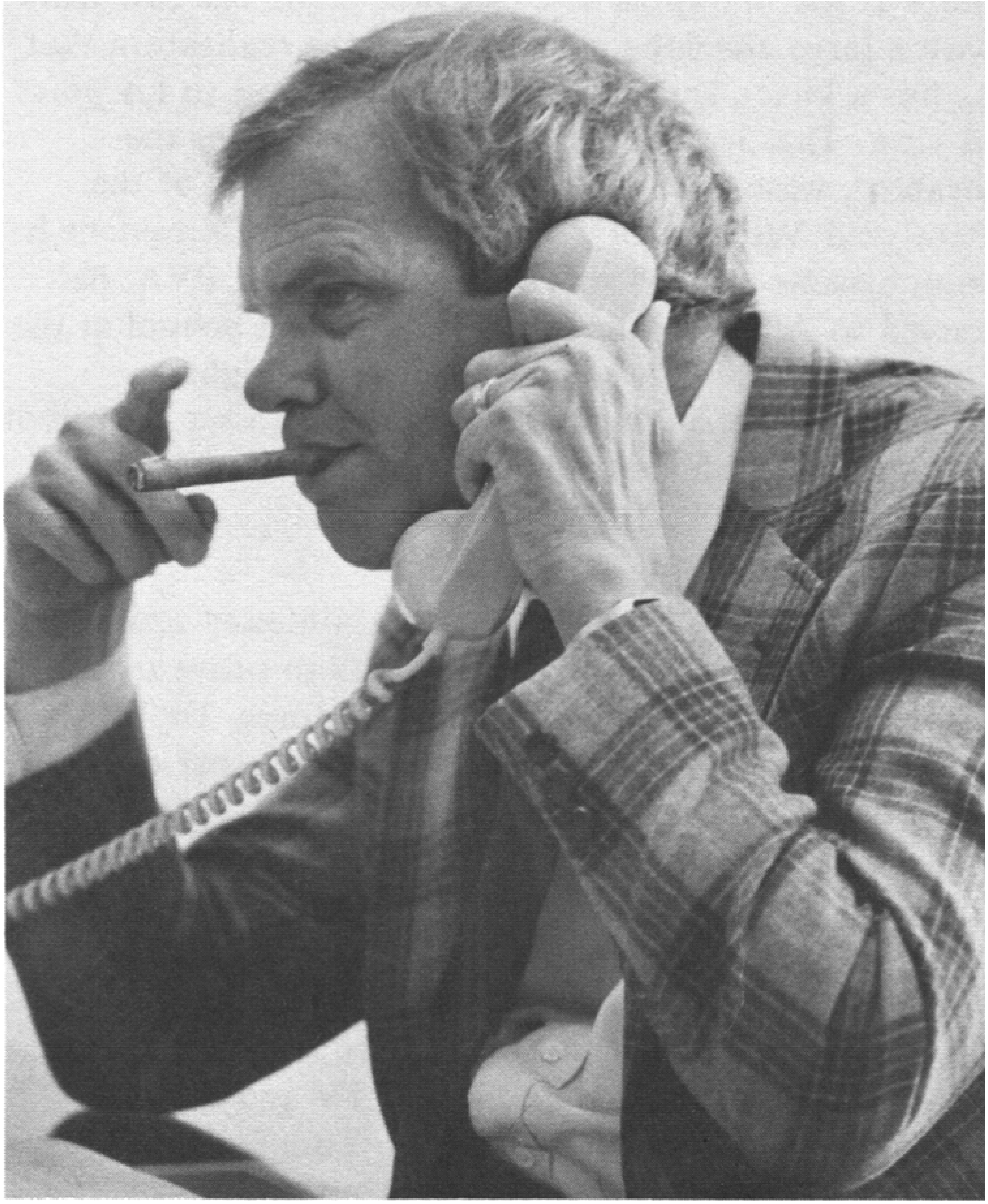
The place is a former service station, ramped, panelled and converted to office and meeting space. Several friendly people in chairs are moving about, stacking literature, answering a constant clamor of telephones and coffeeing up. In the main office, I hear snatches of phone conversations:

- Are you talking about the Section H Subsidy?
- That’s preferential treatment! Do it for one, do it for all.
- You think *that’s* a barrier? How about…

This place means business. I roll around a partition and find Tom on the phone, so I look around and listen. There's a small American flag on his desk, and stacks of legal books, books on barrier-free design, the SCI Manual, HUD manuals —tools of his trade.

Right now he's talking to a newspaper reporter about the very hot issue of accessible transit: "The price of the lift is $14,000, and they're talking about $20,000 now, which is a bald-faced bug-eyed crooked-tongued rip-off. Those boys are trying to make up the inflationary cost of bus prices on those lifts."

Tom's a politician, a patent medicine huckster, one of those folksy types who can wrap spider webs of logic, charm, persuasion and pugnacity around any discussion. On the subject of a recent meeting held to discuss making city council meetings accessible, when all attending wheelers were hauled up a flight of stairs to the meeting room by firemen rather than meeting in the already accessible library downstairs, Tom explains to the reporter: "The mayor's a chain smoker, and he wasn't willing to abdicate his right to smoke." End of communication. Tom turns to me, grins mischievously: "Medivac and advanced medical care have made me a terrible pain in the mayor's side."



Hot tip: “I think the first thing a person oughta do is get out of that damn hospital environment, because it’ll kill you. They’re going to treat you as a disabled person and the longer you stay there, the more reliant you become, the thicker that umbilical cord becomes and suddenly you can’t get out. Initially, the philosophy for SCI’s was: Oh poor dear, he’s not gonna live long. So let him live fast, love hard, die young and leave a beautiful memory. He could get away with anything, but he didn’t get very far from the hospital.”

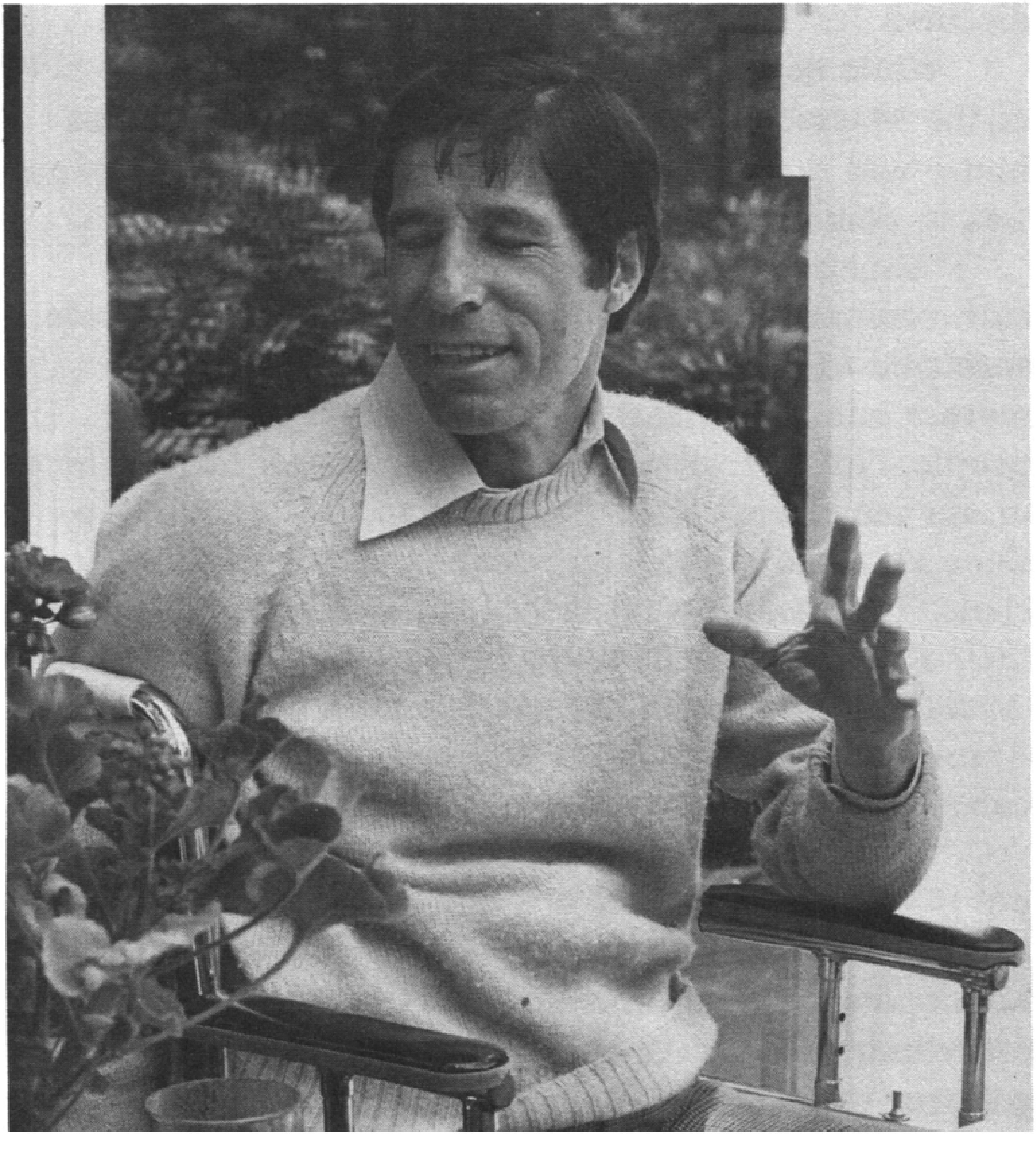
He feels that there are still what he calls Hospital Homesteaders: “They never leave the hospital. They *couldn’t*. They’re frightened to death that if that bed was not available for them, they would have to go outside that door into the big, mean, ugly world. And if you let the hospital environment stay with you long enough, it’ll do that to you.”

So Tom Deniston has flown his airplane again and cemented his family bonds. As for his occupational objectives: “By having that injury, I found not only a job that I enjoy doing, but I’m also helping people. At least I think I am, as an advocate for handicapped people. (He lightens up a little, smiles wistfully) It’s a shame I had to break my neck to do it…”

6.14.2 Frank Musinsky

Yale, BA in English literature and history, copy boy for the *New York Times*, playwright, dialog director for Universal Studios, independent producer in Hollywood and overseas, and, as a refugee from television’s rearrangement of the motion picture industry, the head of marketing for five shoe factories. He has a gracious wife, Bonny, three children and a beautiful home in Weston, a suburb of Boston. In 1971, Frank was 40 years old.

That year, when Hurricane Doria was stomping the eastern seaboard, Frank was out driving his VW on the Mass Pike. A capricious gust of wind flipped him. T6,7. Local hospital, immediate laminectomy; survived a pulmonary embolism, transferred to Boston University (Regional SCI Center) “and learned what it’s all about.”



One of the things he apparently knew innately, something that several people in these pages have suggested, was to get back as quickly as possible to what he was doing before.

At his request, he was moved to the Extended Care Unit so that he could become independent of the help of nurses and aides and get back to work. He wanted to know if he could still manage. He'd catch a cab every morning, go to his office, get carried up a flight of stairs and return to ECU at the end of the day.

What he found at work is what he knew all along; he couldn't do the amount of traveling required by his old job. So he applied to a different division of his company (SCOA Industries, now a mini-conglomerate) and was hired as an advertising executive for Hill's Department Stores, a SCOA-owned chain which has grown from 30 to 80 stores during Frank's tenure there. He likes his company and he likes the work. "I'm the only person in a wheelchair working for the company, and we employ 12,000 people. I don't consider that to be bending over backwards on behalf of the disabled . . ." But they've treated him well.

While he was still in the hospital, and with the help of the Massachusetts Rehabilitation Commission, his house was ramped and made otherwise accessible. How was it, coming home?

"Superficially, very easy. My wife is an extraordinary woman from the standpoint of the wide spectrum of patience that she has and the tremendously mature and open-hearted responses that she has to people. Not just to me. So there was never any problem in our marriage." Superficially, it seems, because the three kids had a hard time dealing with Dad being in a chair. They didn't want to hear or talk about it, and their son tended to deny the injury emotionally. "He would still very much like me not to be in the chair." Frank and Bonny see time and maturity as the best cures. The discussion did bring out this advice.

"Anyone who's newly injured, who's going to go out in the world, should not think that everything is a bed of roses, because that isn't true. You can accomplish an awful lot. You can't accomplish everything. There will be stumbling blocks that you will get over through getting involved in other things, *getting outside of yourself*. Then there are other hurdles that you don't think you can jump over, and you're going to be very surprised that, God —you get out there and it's nothing. Absolutely nothing."

How about other disabled people? "For the first year after my accident I found myself avoiding contact with other people in wheelchairs. As I look back upon it, I was looking at my other self. I was seeing what other people looked like in chairs, and I didn't like the look. And because I didn't like the look, I wanted to avoid it. What I learned, however, is that it really didn't matter how I perceived what they look like, it mattered how able bodied people perceive them. I saw that they felt quite natural with people in wheelchairs. Why shouldn't I, in a wheelchair, feel equally natural? And gradually the barriers came down."

Now: "I think it's important to spend time with other people in wheelchairs so that one doesn't feel completely disaffected with oneself. If you're only around people who are able bodied, you may, over a period of time, actually think there's something wrong with you. And there *is* nothing wrong with you. I don't say that you have a mission in life to spend time only with people who are disabled. That's as ridiculous as spending no time."

Here's Frank being non-discriminatory in his relationships. Bonny, his wife, has a cast on her broken leg. Bruce Marquis, Executive Director of NSCIF, is on crutches and has a cast on his torn Achilles' tendon. Barbara Langdon, on the right, is temporarily able bodied.

More advice: “Develop a relationship with at least one person you trust to the extent that whatever has happened to you has absolutely no relevance in your relationship.” And: “Whether you’re a male or a female, get yourself into bed with someone of the opposite sex, or even of the same sex as far as I’m concerned, as quickly as you possibly can.”

Hot tip: “Don’t do what I always do, which is to put the chair arm on the roof, get into the car, take off and lose the arm. Thirty-five dollars an arm. Be careful.” What kind of arms do you buy? “Generally, Schwarzenegger arms.”

6.14.3 Ed Eckenhoff

The Midwestern Regional SCI Unit is at the Rehabilitation Institute of Chicago and Northwestern Memorial Hospital. Like most of this country’s premiere rehabilitation establishments, RIC had humble beginnings in an old warehouse that nobody else wanted. Today, it’s a soaring glass and steel tower standing between Lake Michigan and the hospital.

On the fifteenth floor, we’re talking to Ed Eckenhoff, Vice President and Administrator of RIC. Once the camera, recorder and lights are on, I open with this splendid icebreaker:

What do you do for a living? (Good crisp, to-the-point question.)

“I run a hospital.” (Good crisp, to-the-point answer.)

That’s ridiculous. Why would a gimp run a hospital? (Loosen it up, give him something to respond to.)

“I beg your pardon?” (Ooops.)

Why would a gimp run a hospital? (Bravely, brazenly, I repeat.)

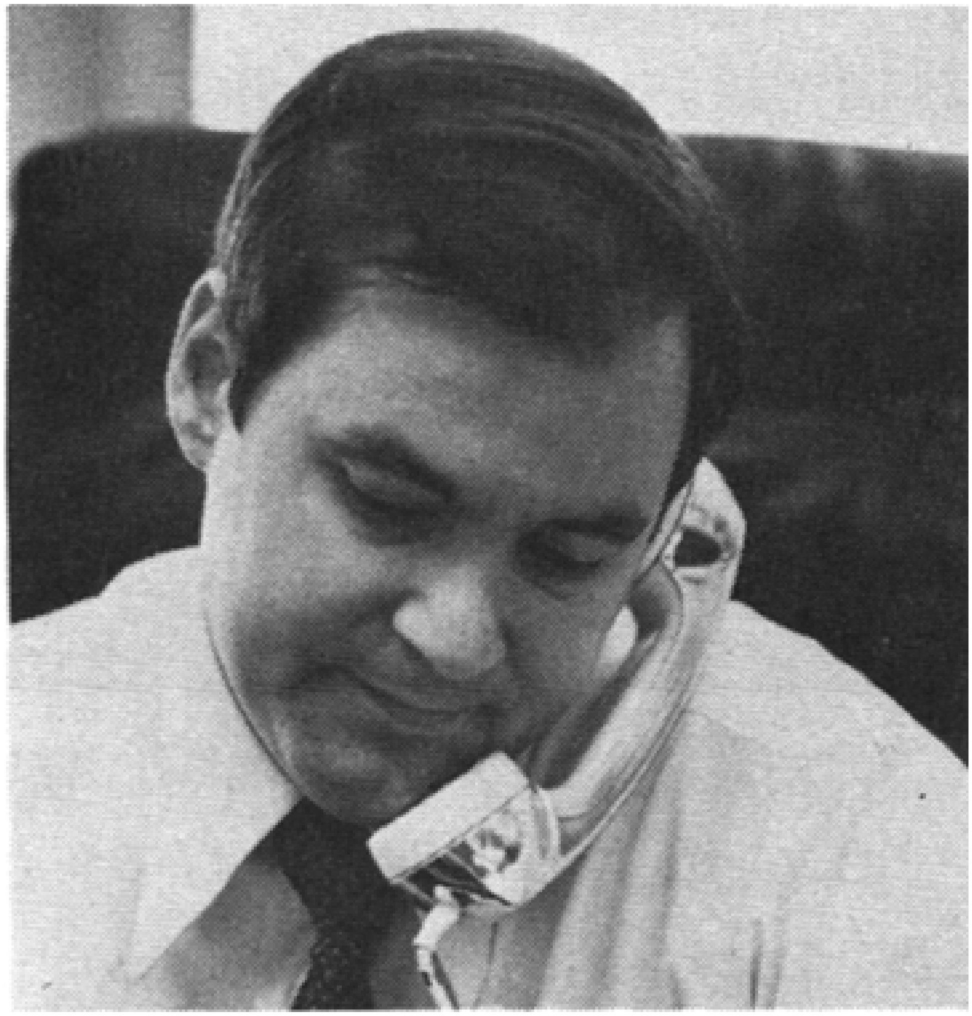
“Why would a what?”

A gimp.

“A gimp. What’s that?”

Cut.

So it was that Ed Eckenhoff, Administrator of RIC, auto wreck survivor, T11 paraplegic for 16 years, first heard that word. It was, to be sure, the only gap in his knowledge to be found. In his job he’s responsible for over 30 departments and 700 employees of the largest comprehensive rehabilitation facility in the country. He knows a lot about gimps.



As he sits behind his desk in a conventional swivel chair, one is hard put to discover a disability. No wheelchair. Except for the vasty corridors of O’Hare Airport, he has always used braces and crutches to get where he’s going. Why braces?

“I like to walk. I like athletics. I’ve always been very active — playing football, tennis, swimming, skiing — so to a certain extent, this was just another sport; something I had to win at. And I like to win.

“I like to be as tall as I can. I can still be boisterous, yell, rant and rave, knock doors down— yeah, and get knocked over—and I like to be physically tired at times. So I walk.”

He walked from his rehabilitation at the University of Pennsylvania back to college after missing only one semester. How was it? How about dating?

“I thought I was going to be very limited. That’s what happens when you’re recuperating and you’re thinking the worst and you’re always tending to be a bit negative and not giving yourself enough credit. I thought I’d have a lot of problems.

I am not going to tell you how well I fared, unless you promise not to tell my mother." (Ed hastens to point out that he no longer dates. He's been happily married for a year.)

President of his fraternity, vice president of his senior class, he left with a master's degree in psychology. After four years of counseling in a large school system, he dropped everything, went to Washington University in Saint Louis and emerged with a degree in health care administration. That led to a residency at Northwestern Memorial Hospital and thence to RIC.

Ed emphasizes the fact that he came from a very competitive, achievement-oriented environment. His father, for example, is dean of a large medical school, one brother is an architect, another is a physician and the third is a biochemist. Yet what strikes me is that the entire world is Ed's apple by virtue of the fact that he *thinks* it is.

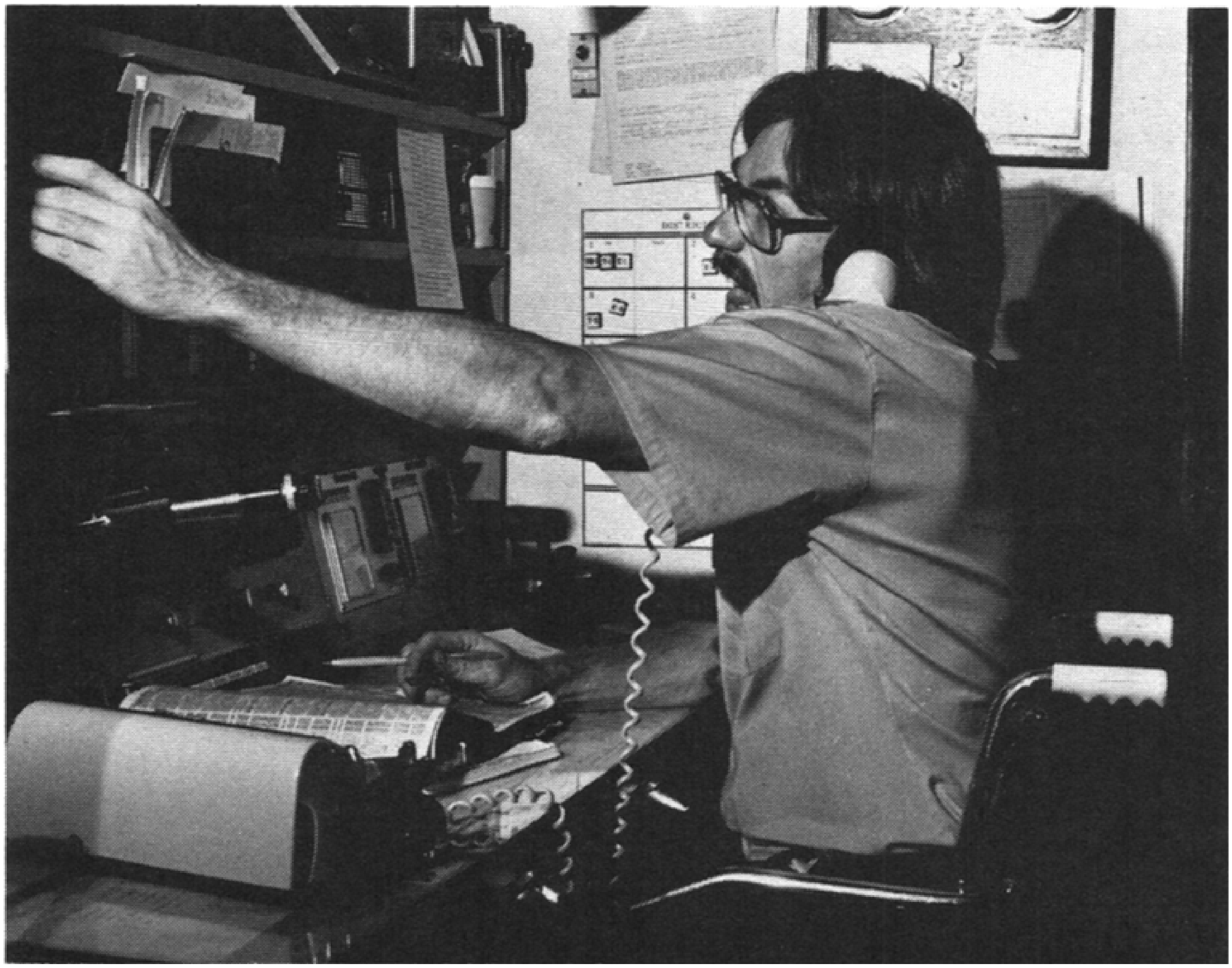
"I've been in a couple of different professional fields; who knows where I'll be in five years? Hobbies have taken me in various directions — furniture making, collecting eighteenth century furniture and art, which makes you wonder, Jeez, maybe he'd like to become a curator some day, and there's no reason why I couldn't do that. I played the piano for 14, 15 years and there is no reason why, if I had practiced six hours a day, I couldn't have been a concert pianist. I've done a lot of different things and that's, I suppose, why I'm not too terribly depressed or upset about my disability. There's just a hell of a lot of options.

"Rarely, unless you're in sports, is a physical disability going to impair what you can do. We strain a little bit more, we have to be a bit more competitive, we have to sell ourselves a bit better; but I've had no problem in doing that and I would like to think that most people would have no problem in doing that.

"Your potential is guided by your outlook on life. It's simple!" Yup.

6.14.4 Buzz Hicks

A young man is alone in a dispatching room designed to accommodate only two situations, sheer boredom and dire emergency. At one end are an easy chair, a color television and a microwave oven. At the other end are radio console, CB scanner, paging system, city and county maps, files of location cards and a telephone. In Buzz Hicks' case, there's also a Bible.



- Buzz: Engine 2; dispatch.

  (Radio: blat, bleep, scratch, burp — Engine 2 acknowledges)

- Buzz: Chief one has been notified.

  (Radio: Roger.) (Phone rings)

- Buzz: Fire emergency. Yes ma'am … What's your address? 361 Magnolia. Your drapes in the front room. What's your phone number, ma'am? Your *phone number*. 482-1131. OK, we'll get someone there right away.

  (Consults location cards, then punches buttons on console.)

- Buzz: Engine 4, truck 1, squad 1 —361 Magnolia. Drapes on fire. Group 2913. (Phone rings)

- Buzz: Fort Collins Fire Department. Yeah.

  Yes. We've got gas leaking in a sewer system at Campus West. Can you hold on a second?

  (To radio)

  Engine 2, dispatch. I'm unable to find

  Bureau 2, Bureau 3 is on the line. He's willing to come out there.

  (Blat, bleep, static of radio responding.)

- Buzz: Roger. 17:25.

Buzz has a lot of responsibility, not too removed from that of an air traffic controller. He is a dispatcher for eight fire stations and all emergency health vehicles in a 250 square mile area. Daily, or nightly, he contributes directly to the welfare and safety of the city of Fort Collins and its satellite towns. At the end of his 12 hour shift, he wheels to his Volvo and drives home. He has the air of a man who likes his job but is now heading back to the important part of his life.

In 1971, Buzz had a high school diploma and a bunch of problems. He was depressed, a self-acknowledged doper and freak, and things were not going at all well. He and a friend had aborted a trip to Central America after rolling their car, and they were hitch hiking home. As he was walking along a highway near San Antonio, his back to the traffic, he was hit by a car. He's a T3.

Buzz had a desperate time finding this job. "I just went into the Fire Department to talk to the chief, and he thought I could do it and I thought I could do it, and they took the ad out of the paper and I got hired." That's all. His formal education still stops with high school, although since his accident he has taken a personal tax course and augments his living by consulting.

For recreation, he drives a lot, rides his Centauri (an arm-powered trike), fishes and occasionally works out in a local gym. He has canoed on flat water and has dumped, which probably means he swims. He plays guitar with a band of friends.

He has been married and divorced since his accident, and doesn't really know why it didn't work out. He says he would remarry, "but not just to fill a void in my life." He now lives with two roommates in a rented home and seems extremely healthy and happy. You can see it in his body, his eyes and what he says. And it's not at all difficult to find out what makes him that way.

Buzz joined what he calls a "fellowship of Christian believers who've been looking towards a committed life together, living out our lives as a family." It has become a life that he wouldn't and couldn't give up, and it is obvious that his entire sense of completeness issues from this group and this lifestyle. On Buzz, it sits well: "It's something I've been brought into by the Lord, and He's really changed my heart and my mind about a lot of things —and that is being committed to other people and living my life out for other people."

Now when I hear someone talk that easily about the Lord, I usually keep one hand on my wallet. Not so with Buzz. He's got a light, a Lord and a true extended family. I envy him. I envy him and his ability to say these things:

"I think we can look way above it and look out of ourselves and look *at* other people and try to focus our love towards *them* instead of trying to establish our own selves. I think in loving others, we then become grounded. Grounded in love.

"I think it's easy for us to get ourselves focussed on where we're at instead of where we *can* be at in other people's lives.

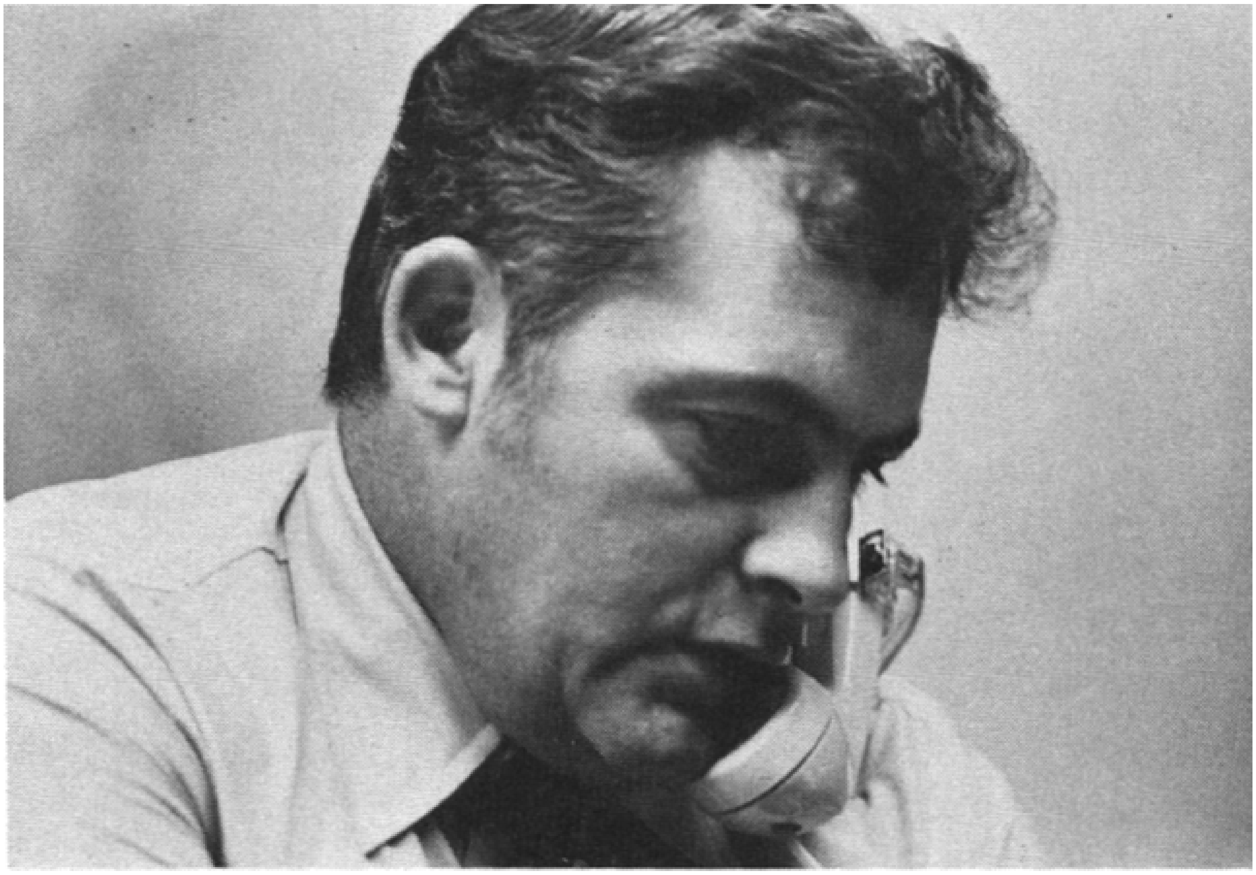
"I'm seeing now that I really must function *in* my wheelchair, *in* society. I think this will get us out of the dependency upon our handicaps and start depending on the life and the love that's around us."

There's a lot of life and love around Buzz. You can see it when he comes in for another 12 hour shift (four days on, four days off). His co-workers are drawn to him, want to know what he's been doing on his days off. There's the normal horseplay that exists wherever men are bored because they are waiting to be scared by the next emergency, but the usual profanity is missing. Does the Bible Buzz carries really negate the working man's God-given right to use His name in vain?

Buzz doesn't preach. These men are not members of his Fellowship. Or are they? In a very broad sense, they must feel that they are.

6.14.5 Cliff Crase

This profile is a quickie, partly because Cliff is already well known, and partly because I caught him just before the deadline of one of the magazines he edits and he understandably couldn't spare me a lot of time.



Cliff's accident was in 1959, a sports car wreck while returning to his air base in Minnesota. He was 21 years old. C6,7. He's a quiet-spoken man who still feels sports to be near the core of his existence, a fact which shows in his massive upper body and craggy features.

After rehabilitation, and after a couple of years in his native upper Michigan, he went to the University of Illinois, took a lot of business courses and a few in advertising, got his degree and became a stock broker.

But before he left the University, he got hooked on wheelchair sports. He'd been an all-state basketball player, had played a lot in the Air Force, so sports were very important to him. Since quads normally don't get to play much in wheelchair basketball games, he got on the swimming and track teams which in turn provided his ticket to the National Games.

So, as the stock brokerage game changed through the years, becoming centralized in four or five corporations, Cliff just leaned with the wind and concentrated on analyzing and consulting. During the same years, he qualified for 10 different US teams that went all over the world. He specialized in pentathlon, did a lot of winning and a lot of traveling.

In 1969, he married Nancy. That was the year he started writing a monthly wheelchair sports section for *Paraplegia News*, a magazine owned by the Paralyzed Veterans of America. He also became Sports Coordinator for PVA and served on its Investments Committee. He still hold both posts.

In 1975, he and Nancy started their own magazine, *Sports 'n Spokes*, as a back room operation. It's a front room operation now, but it doesn't look like the *Washington Post's* newsroom. It's a small magazine targeted at the jock minority within the handicapped minority.

In 1978, Cliff's close friend and long-time editor of *Paraplegia News*, Bob Webb, died. Cliff flew out to Los Angeles to deliver the eulogy, and didn't give the magazine another thought until he was suddenly drafted as its editor. So now Cliff and Nancy have two deadlines instead of one, two magazines to put to bed, 28,000 readers to satisfy and I can't understand why Cliff hasn't thrown me out of his office yet.

His parting words let you know what's still important to him: "Paraplegics, or the parents or wives of paraplegics, can't picture someone scuba diving or kayaking or marathoning like they do, and they write in and say That's totally impossible. And the magazine says, IT ISN'T TOTALLY IMPOSSIBLE. JOE BLOW DOES IT!"

6.14.6 Don Rugg

1954. Don was newly married and had just graduated with a degree in electrical engineering from Denver University. Car wreck. C5. Poor timing, personally and historically, because medicine's ability to deal with quadriplegia wasn't too finely honed in 1954.

Don spent a year at a general hospital cooking up pressure sores, then a half year healing them at Colorado General in Denver. By 1956, he could still only sit for four hours at a maximum because his skin wouldn't tolerate longer periods and he didn't have the upper body strength to shift his weight. This was disturbing, to say the least, and nobody had any idea how to overcome the problem.

Except Don. Like many others in this book, he found the answers within himself because they didn't exist anywhere else. Necessity *is* the mother of invention, and Don started visualizing in his mind an electric wheelchair that could shift his weight for him. He teamed up with a friend, a mechanical engineer, who produced and assembled the parts. He was strongly encouraged by his doctor at Colorado General, a maverick named John Young who went on to start Craig Hospital and later brought enlightened SCI care to Good Samaritan Hospital in Phoenix. After months of stop-and-go frustrations, Don had his first reclining electric wheelchair.

"It was one of those things that worked out far better than what one might expect it to in the beginning, because from that time on I haven't been hospitalized once with a pressure sore. Without the reclining chair, I had to be moved physically from the wheelchair and laid down about every four hours. Now I can stay in the chair for 16 hours a day. It's allowed me to work full-time, where before I had to work half-time."

During those early years, did he ever want to give up and quit? "Whenever you end up a quadriplegic, it's very difficult to say OK, I'm not going to do anything, because at that point there's not a damn thing you can do anyway. I was not doing anything to give up! But I also was not very content with doing nothing. I think there is an adjustment period there after you do nothing for an extended period of time. You realize that it is not a viable alternative to living.

"When you lose so much physical use of your body, it does really destroy one's self-image. There's no getting around that. And it also destroys one's self-confidence. At this time it's really crucial for the people around you to help restore that. And then after it once starts coming back, then it's a snowballing effect. As you start gaining more self-confidence, then your interaction with the people around you becomes more positive, which reinforces it."

Snowballing: By 1958, he had his master's and a part-time job at the Denver Research Institute (the research arm of DU). By 1960, he was working full-time and handling three additional hours of night classes. By 1968, he had his doctorate. How did he get all this education? Was he rich?

"No! I'm a farmer. I came to Denver on a scholarship, I got my master's degree through the Department of Vocational Rehabilitation, and I got my PhD through the fringe benefits of working at the University of Denver."

His vocational interest is in the propagation of very low frequency waves, and his work is mainly the analysis and theoretical review of data and the consequent design of devices based on theory. How does he handle lab work?

"Whenever I'm in the lab, it's usually directing an experimental set-up, having the technician take the data. I am limited in doing some of the lab work that the other engineers do for themselves, but this is no fundamental limitation on what I can do, what I can achieve."

More on support: "I think anyone with a severe disability, that their accomplishments are largely affected by the attitudes of the people around them. I've been really fortunate in having a wife that was always supportive and understanding and did not take anything less than a maximum effort out of me. She also did not take the attitude that it was her duty, and her sole duty, to take care of me for the rest of my life."

Here's a quarter century of marriage and a quarter century of SCI. Any comment?

"I honestly believe that a SCI has never helped any marriage, any more than it helps in any other thing. It'd be a heck of a lot easier to do without the SCI. So I've never been one to say I'm blessed because I got my neck broke. The problems that arise —there are problems as in any marriage —they're different. We have, by luck or somehow, worked out the problems."

Don is saddened by people who wait around for a cure. But what if there *were* one? "If there's a miracle cure that comes along, then fine. A lot of my problems will be over. And probably a lot of new ones would creep in." Jeez, just think of the trauma of dealing with an able body after all these years. "Right! But I figure that if I can handle the situation as it exists today, I could damn sure handle it if I suddenly was not paralyzed."

6.14.7 Judy Gilliom

Remember those science fiction movies and books about a central intelligence which ran the entire show in its part of the universe? It was a being that could juggle quarks and quasars and anti-matter and black holes without moving a motor neuron. Sometimes it was depicted as a gyroscopically swivelling eye or sometimes as a container full of pulsing protoplasm. This intelligence needed no arms and legs because all the events it initiated were mind and energy transactions. If you're in the central intelligence game, CIA excluded, you get things done by creating and manipulating energy patterns.

Judy doesn't swivel or pulse. She'll be the first to tell you she *does* nothing. But somehow, she gets things done with astounding efficiency. Of all the people in this book, Judy has the least physical function left to her. Of all the people in this book, none is more functional.

One of the things central intelligences apparently aren't supposed to do is housework. In 1970, Judy fell from a kitchen counter while cleaning cabinets. C4,5. Bad mistake. She was 26, managing editor of a magazine, and knew she had no business cleaning kitchen cabinets.

She stayed three months in acute care, surviving against predictions, then spent eight months at one of the country's best known rehab centers. It shall remain nameless, lest I slander an institution that has done well for many of us, yet Judy's observations are pertinent to anyone associated with rehabilitation work.

"Those who are injured when they are adolescents and don't really have formed personalities when they go there are able to deal with the kind of condescending, dictatorial, pushing and shoving approach they take there. Whereas people who are pretty much adults at the time they arrive find it more debilitating than the injury. That was the experience I had."

Mostly, she couldn't understand why the Very Famous Medical Director was always off in Amsterdam or Sydney giving speeches about paralysis and human dignity, while back on the home front she was getting bad advice and pressure sores.

The advice she got, basically, was to learn to type with sticks and slings and pulleys. An engineer-friend took one look at the equipment she'd been sent home with and advised her to get rid of it all and hire a person. So began her credo on adaptive devices:

"The fewer you have, the better off you are. Junk, basically, gets in your way. If it's wires, leather, metal, it will break down. And the less you are dependent upon something you can't control, the better. Strangely, one of the easiest things to control, in that respect, is another person. (Here comes the real Judy Gilliom.) It makes very little sense for me to try to sign a check with a pencil in my teeth when I can get a secretary to sign it for me with her initials under my name or when I can give someone a power of attorney to handle a checking account for me. The amount of energy I have to put into struggling with devices simply is not worth it. I don't have that kind of energy to expend, and for a disabled person, time is of the essence. If you can use time well, then you can do the most that you're capable of doing. These trade-offs are important, and making the right decisions makes the difference between whether of not you'll spend all your life trying to overcome a disability, which is a thing you really can't do in terms of changing yourself so you're not disabled, or spending your life forgetting about the disability and being what you are."

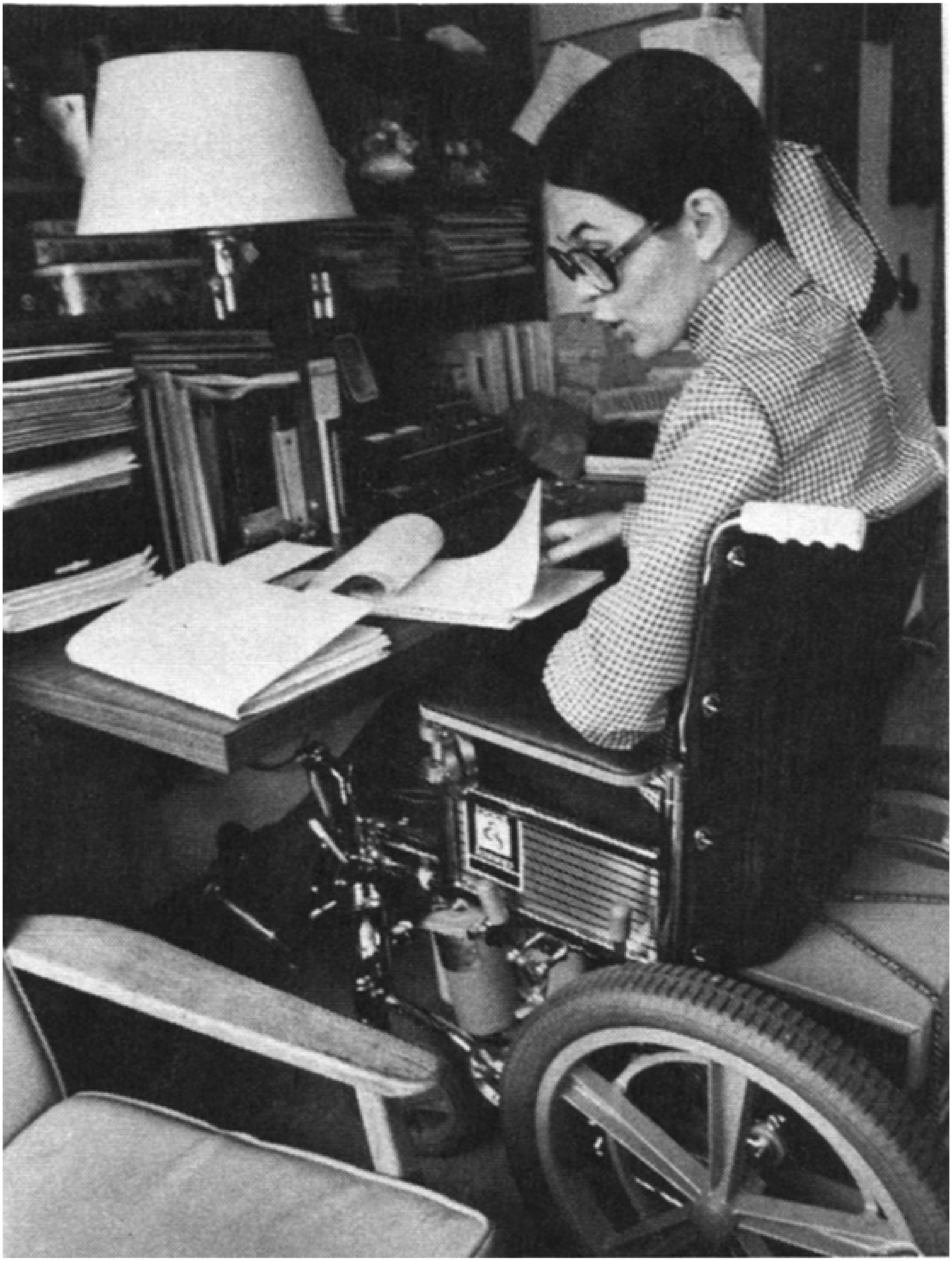
She does have some favorite mechanical friends: "I live with one hand on that dictation machine. I dictate everything. I tell people what to write on things, how to file things, when to water plants, what to remind me to do and when to come back. It all just goes on the tape. I have a speaker telephone, which works very effectively if you don't mind sounding like you're in the bottom of a well. Let's see, what other devices? Power wheelchair. And these wrist extension splints. A sitting brace."

She has a van. Does she drive?

“On no indeed! I don’t *do* anything. I drink out of a long straw, I use a dictation machine, I use a telephone, I talk a lot, I give orders. I’m very good at giving orders. But I don’t do anything. That’s not my bag, doing things.” Her bag is getting things done.

The basic decision, then was that for a high quad, a human being is the most reliable and flexible adaptive device available. Judy doesn’t mean a slave, a robot or even an attendant. She organizes whole batteries of people to become operative extensions of her own remarkable brain. Judy and her people interact with a mutual sense of respect and privilege, and the symbiosis is nice to watch.

Here’s another example of maximal efficiency. Judy *chooses* to live in a nursing home.



“A lot of people seem to feel that if they end up in a nursing home, that’s the end of life and they will never see daylight or any of their friends again. One of the facts about a nursing home is that it's one of the most efficient mechanisms for getting an unwieldy body attended to. It keeps my body out of the way; *they're* responsible for taking care of all the details. I have a full-time job and heavy volunteer activities. If I had to devote a lot of time to administering a mini-institution in my own behalf, I wouldn't be able to do what I want to do. I don't choose to spend my time that way.

"Sometimes it seems emotionally more appealing to live in a house. But a house is smaller; you can be trapped there rather than simply encased in privacy. The nursing home has a lot of space and a lot of staff, and the economies of scale make a lot of difference when they mean that you're able to come and go as you please. If I arrive at two o'clock in the morning, there are people waiting to put me to bed. I really could not afford to hire someone to sit in my own house and do that for me."

Once seen, the nursing home makes lots of sense. Judy's social life is in no way defined by the predominantly geriatric population of the home, for example, because her friends live elsewhere. "They come in when they come in and we go out when we go out." There's a large patio for entertaining, and one of the filing cabinets in her room is actually a bar. There's also the everpresent dictating machine and two desks. Many of her working hours are spent here, often with one or more secretaries, so it's much more than just a bedroom. It's a very tightly designed office that happens to have a bed and a bathroom.

With her basic living decisions made, Judy returned to her editing job and held it for another five years. That led to consulting jobs, developing policy and procedure in disability-related fields. She freelanced for the National Endowment for the Arts, consulted for the Office of Independent Living for the Disabled at HUD, served on the President's Committee on the Employment of the Handicapped and also on the President's Committee on Retardation. The nursing home was a humming place in those days, a nerve center for Judy's far-flung mind network. At that time, she had three secretaries working for her and her three dictation machines were working overtime. And now this job:

"I work for the Interagency Committee on Handicapped Employees. It's a group that's able to consider issues and difficulties and barriers to employment of persons with disabilities. Because of the composition of the Committee —eight agency heads — generally we are very effective in getting things changed, in getting policies implemented very quickly. It's a place where I feel I've been able to have some effect and have been able to see things happening, and that's not always the story in government jobs."

Here's a hot tip: "Take charge of your own life. There are a lot of people who will try and tell you that they will do it for you or will imply that somehow or other they will carry part of whatever you consider your burden. But the real fact of the matter is that you are going to have to live your own life and that's really the way that's most fun."

And another. It's not what everyone wants to hear, perhaps not what everyone needs to hear, but it's real to a lot of people: "I think that one of the most important things you can do is to give up hope. There's a division of opinion in this field, I think, as to whether or not a person with a disability should maintain hope and always feel that life will improve and things are bound to get better, and you never know quite where your life will end up. That's one point of view. I find it very counterproductive. The most important thing that happened to me was to have a few of my friends say to me, Look! Here it is! There you are. You go on with what you have from here. As soon as you can manage to give up the hope that things are going to be different, you can get about your life and do what you need to do and have a very good time being the person you are.

"A question that's often asked persons in wheelchairs is, What would you give in order to get out? I find, as the years pass, that the answer is, *Less and less*." Has it been good or has it been bad? "It's been very good. Really, I think that my good luck is almost as phenomenal as my bad luck."

6.14.8 Susan Schapiro

Here's a Cinderella story. Susan was hurt in a car accident in 1967, when she was young, vulnerable and scared. Her first obstacle was simply leaving the hospital.

"I was there for eight months, which was really much too long considering what I actually did when I was there. But I didn't want to go home, either, because it was very safe being at the hospital and nobody stared at me and it was pretty easy to live and I knew that once I got out into the real world, everything was going to be horrible."

And was it horrible?

"Yeah! At first. I was 14 when I had my accident, and I had just turned 15 when I left the rehab center. Nobody at the center ever talked to us about what it was going to be like. I just figured that, being disabled, I was a social outcast and I could never have any friends and nobody would want to be around me. It was really bad. And a lot of what made it bad was my expectation that that was the way it had to be.

"When you're 14, you don't have many ways of coping with things like that. You want to be pretty and popular, and a lot of fairly superficial things seem really important. You don't have a good perspective on what *are* the important things." Mostly, she felt "ugly and klunky."

Since life goes on even for distraught teenagers, and since, for Susan, a college education had always been a foregone conclusion, she went to “the only decent accessible school we could find,” which was, of course, the University of Illinois at Champaign. (By this time, U of I was far from alone on the list of accessible universities, but the word was slow in getting out.)

“I moved to Berkeley right after college and spent a year living here and working. There are a lot of places in the country where there are a lot of disabled people who are active, but there’s no place as highly politicized as Berkeley. And I just throve on it. When I came here, I got involved in the disability movement. If you’re politically interested, especially in the politics of disability, it’s very hard not to get caught up in things once you get here —this area is so charged with activity. And there’s a real strong feeling here that you’re OK, even if you’re disabled. It’s not something to be ashamed of. You’re not inferior. I had never been anywhere before where that was the general feeling. It *is* easier to be disabled in some places than in others, and this is one of the easier places.”

How were you doing with your ugly duckling feelings?

“I stopped feeling that way the majority of the time about four years ago. It was a long, slow process. Some of it was just getting older and getting a clear idea of who I was and what it meant just to be a person in general. Some of it was getting positive reinforcement from other people, and especially other disabled people. Some of it was a real concentrated effort on my part, sort of working on myself to *make* myself feel differently after I realized that it might be possible. See, for a long time I didn’t even realize that it was possible to feel OK.

“Then I started to realize that I could still have friends. My normal personality is to be pretty noisy, make a lot of jokes, be outgoing. After I became disabled, I became very quiet and self-conscious and mousey. And I found out that when I lost my self-consciousness or when I was just feeling OK about myself, people still did pick up on things in my personality that they had always picked up on. I found out that even men would do that. I started to find out that I could even have lovers.

“There’s a sort of process—I used to pretend that I didn’t mind being disabled, or I would pretend that I wasn’t aware of it, as a way of not being self-conscious. It wasn’t even a matter of being brave. I realized that when I wasn’t thinking about being disabled, or when I wasn’t worried about being rejected for being disabled, other people didn’t reject me because there was a whole self-conscious air that I would lose. When you set yourself up and all you’re telling yourself is, I’m-awful-and-I-know-you’re-going-to-hate-me, that’s what people pick up on. And when your inner feeling is that there’s no reason that people shouldn’t like you, that’s what they pick up on. So I used to pretend that I felt that way even when I didn’t, and the more I did that the better I actually felt.”

What prompted you to go to law school?

“I wanted to do something that would have some effect on my life or somebody else’s life. I didn’t want a job which just involved keeping the economy rolling along. I wanted to change the world, just like everybody. And I wanted to be involved in the movement. You know, sort of a professional disabled person, a professional crip, and it seemed that if I had a law degree I’d be a lot more useful.”

In 1978, Susan graduated from law school, passed the bar, and was sworn in. “It’s a beautiful credential to have after your name. There’s sort of a feeling of power being able to tell someone you’re an attorney. And I don’t look my age. I look like a cute little crippled girl; so it’s really important in negotiating settings to have something that gives me clout, even though, in a way, it’s artificial.”

She works in the Disability Law Resource Center, a division of CIL (see *The Berkeley CIL*), along with five other attorneys. The Center deals with disability rights in an overall sense: landlord-tenant problems, employment discrimination complaints, insurance discrimination and education.

“We just finished writing an amicus brief for the Supreme Court. The first 504 case is at the Supreme Court right now, and there’s a chance that they’re going to limit severely the whole interpretation of the law. It puts me right in the forefront of a whole new area of law. There are hardly any precedents yet and the whole thing is burgeoning.”

What else does she do? She gives lectures on sex and disability, mainly to non-disabled audiences. She feels that the general public has a tendency to discount the sexuality of disabled people, to assume that we’re asexual. She also knows she had to educate herself:

“I used to feel that I really couldn’t have real relationships because I thought that, as a disabled woman, I wasn’t as desirable. I figured that there was really no reason for anyone to be interested in me if he could have a woman who could walk, totally discounting my whole self and my uniqueness as a person. I didn’t feel really good about myself until I started feeling sexually attractive, feeling that I could function, not competitively, but on an equal footing with any other woman.”

Sports: “I didn’t consider myself athletic before I broke my back, but I did like to be really active. And then I just stopped. For a long time I felt a real need for ways to expend energy, but somehow the idea of wheelchair sports seemed silly. I guess I was still in my angry stage; I felt that if I couldn’t do stuff the right way, I wasn’t going to do it at all. That’s a really stupid feeling, that one way is right and some other way isn’t. *Any* way you can do something is the right way to do it.”

The missionary position of mobility?

“Exactly. And it’s so stupid. Anyway, I found out that wheelchair sports are a lot of fun.”

She started playing basketball, then gravitated to track events. She pushed the 1978 Boston Marathon. She canoes and rafts and is exploring wind surfing. She’s made films. She co-authored a book. Does one have to be a compulsive overachiever to succeed in disabled life?

“I don’t think you have to be driven by ambition to be able to live happily with a disability. Maybe you need a certain motivation to go out and force yourself to keep living, force yourself to keep being part of the world. But it doesn’t have to be linked with ambition or motivation in other areas of life. You don’t have to be a superachiever to go through the kinds of changes that I went through.

“I think the real secret of making it or being happy is just feeling good about yourself *and doing whatever it takes to make you feel good about yourself*. I’m sometimes driven to achieve because that is one of the things that does make me feel good about myself, but I don’t think everybody needs that in order to become self-satisfied.”

For that counsel, Susan Schapiro, fledgling attorney at law, should send us all a bill.

Then the rains came back to California, and we hustled equipment into the van as Susan hurried back into the two story house which she shares with her boyfriend, another tenant, a dog and a cat. As she skirted the doggy-do on the ramp. I thought of the 14 year old girl who had been so devastated by her accident and asked her what she wanted to do in the future.

“I want to be important. I like to have people know who I am.”

6.15 Life Styles

6.15.1 The Berkeley Crips

I always knew they were crazy in Berkeley. When I was a kid, the crazy rock climbers all came from Berkeley, and then the political activists. Now the crazy wheelers are all there.

For example, Berkeley has curb cuts everywhere. There is no place on Earth with more curb cuts per capita than Berkeley. The only place they *don't* have curb cuts is at street corners. Instead, they put the cuts about 30 feet away from the stop sign or crosswalk, clearly an attempt on the part of the city fathers to eliminate all wheelers by forcing them to J-walk in moving traffic. That, to me, is really crazy.

I asked a local quad why they did a dumb thing like that. Well, schmuck, the reason is that blind people *need* the curbs to define the corners and establish direction. Ramps have very little to say to a white cane.

A little later, I saw two blind women approaching the restaurant on Telegraph Avenue where I was eating. They arrived from different directions, reached the door within microseconds of each other, greeted affectionately, entered, ordered at the counter and easily found their own way to an empty table because the cashier had given them clear instructions. I saw a quad order coffee. He didn't ask for a straw, but he was given one in case he wanted it. It's like that in Berkeley — people there act as if they've been trained in multi-disability rehab centers. There's an awareness of all disabilities and tunnel vision viewpoints such as my own indignation over the curb cuts are not admired.

Actually, no place is that good through and through. But Berkeley, for a disabled person, is very good. This is radical-land, as it has been for years, but the gimps are the most visible rabble rousers in town. They've created a seething crucible of heavy duty disability politics, and are together, effective and militant. They hold sit-ins (what else?), they demonstrate, they bring suit. They also create some backlash from wheelers (see *Mary Wilson*) and the community (they're called CILLIES, after CIL, the Center for Independent Living), but they have made Berkeley a Mecca for anyone who is disabled. "Disabled" is a word that seems to see light only in print and in speeches here. The preferred and operative word is CRIP. If it bothers you, don't go to Berkeley. Berkeley is the way it is, for its crips, largely because of the Berkeley Center for Independent Living.

6.15.2 The Berkeley CIL

For a place that deals with the mobility-impaired, not to mention dozens of other disabilities, CIL is extremely speedy. Outside, vans are constantly arriving and departing. Inside, they're organizing for a protest at BART. Electric chairs avoid collision by microns as their owners zip purposefully around blind corners. Lots of sign language going on. It's a happy, crazy place.

My wheelchair and T12 lesion are no badge of membership here because, by prevailing standards, I've barely sustained a scratch. The variety and severity of disabilities is overwhelming, enlightening and radicalizing. It tends to abruptly pop you out of your SCI rut. There's a lot of other things that can happen to you.

CIL was started in 1972 by disabled people who wanted to integrate themselves and their own into the community. The idea was to get out of institutions or family basements and into homes and jobs. It is, by definition, a community-based nonresidential program. Nobody lives there, and the Center opposes "cripple ghettos," live-in segregated housing. They want genuine integration and genuine independence. The following partial list of services suggests how they achieve their ends.

- Attendant referral
- Housing referral
- Transportation
- Home modification
- Emergency road service

- Peer counseling
- Outreach programs
- Wheelchair repair shop
- Wheelchair design project
- Advocacy
- Legal interpretation
- Benefits counseling
- Disability Law Resources Center
- Anti-discrimination help
- DVR liaison (Ombudsman Program)
- Job development
- Job placement
- Training and education
- Computer training program

Their funding comes from federal, state and city grants, plus increasingly large participation from the private sector in the form of dollars, training and jobs. It's an extremely broad coalition because services are provided for *all* physical disabilities (and some which are not physical), because CIL cooperates closely, often under contract, with government agencies and businesses and because the support of the community-at-large has been successfully enlisted.

6.15.3 Independent Living Programs

While the Berkeley CIL is the first and largest, it is far from being the only organization of its kind. It is now one of over 100 across the nation. If you're feeling long on disability and short on resources, and you want to live independently in your community, it may behoove you to contact the nearest Independent Living Program. It could change your life—in your work, in your contacts with the rest of the world and in the way you live. A list of these programs and centers can be found in the NSCIF National Resource Directory of 1979. Updated lists will presumably be found in subsequent issues of this excellent directory. For some people, independent living programs are the hottest of hot tips.


CiL
PARKING
CENTER F IT LIVING


SPACE AVAILABLE
444-7000
CENTER FOR INDEPENDE LIVING
CENTER FOR INDEPEND

6.16 Lives VII

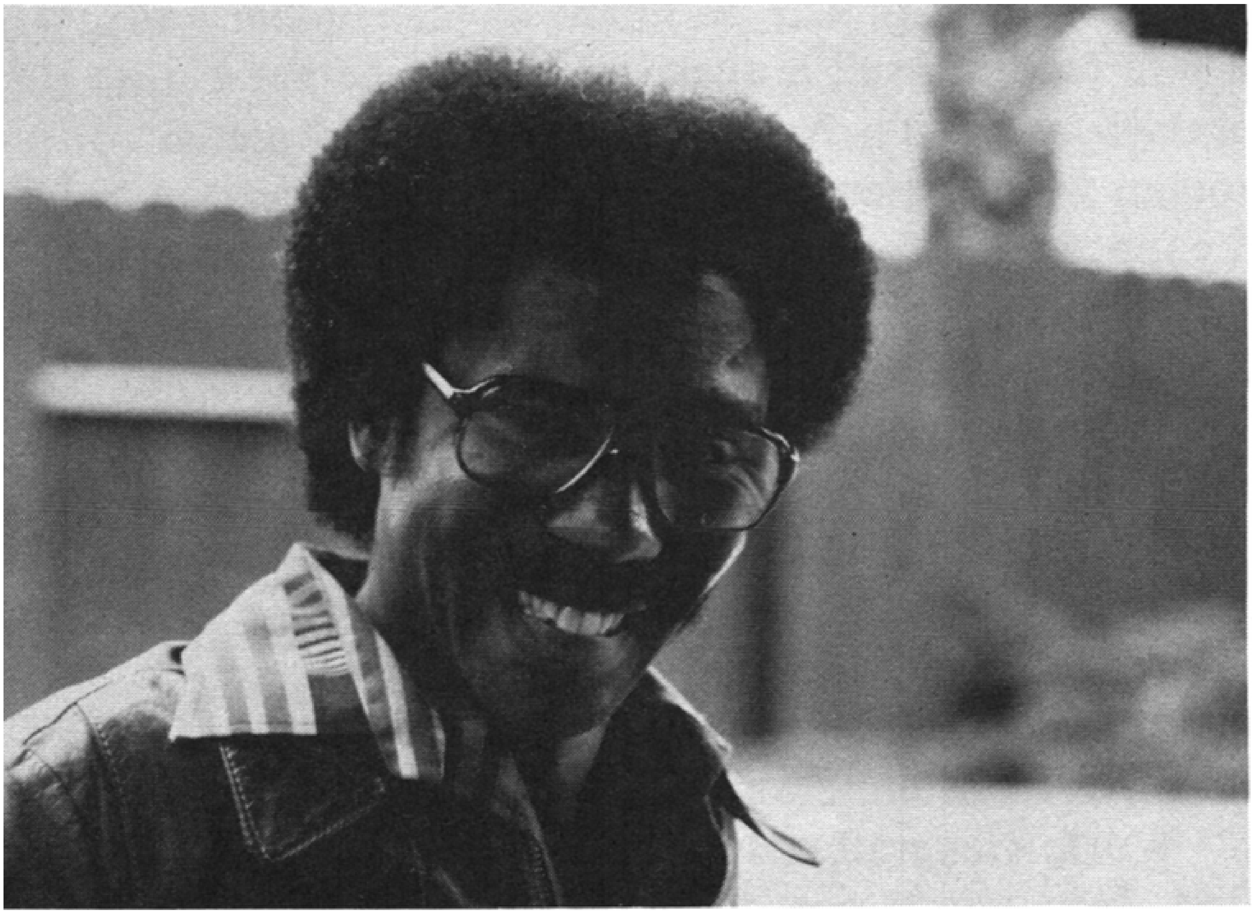
6.16.1 Jim Albert

We'd agreed to meet Jim for lunch at his house in Livermore, California. He'd eat and we'd bug him.

Jim showed up on time, turning the corner in a shock pink Porsche. I later stood corrected: "That car's my heart. That was my thirtieth birthday present (from himself to himself) and it *had* to be that color. It's called magenta."

It's a comfortable house, complete with swimming pool, which Jim shares with his wife of two years. Between munches on a sandwich, Jim tells us about himself.

"Ever since I was a kid, I was fascinated by airplanes. I wanted to become an aeronautical engineer. I wanted to design airplanes. In fact, I did—I had to design an airplane to get out of college and I went to work as an aerodynamicist for Lockheed. But I got into computer simulation doing that. I got turned on by the computer simulation as opposed to the designing of the airplanes. And that's when I had my accident."



Jim did it on a motorcycle. "My first and last ride. Yeah, the first time I'd ever *seen* a motorcycle." He was 21, a T5,6,7 para, and, after three months of head-to-toe pressure sores at a general hospital and another three months of repair work at a rehabilitation center, he was once again confronted with a career choice.

"So when I went back to college, I had to decide which I like doing most. Do I want to continue playing with airplanes or do I want to start playing with computers? And I decided, well, I wanted to play with airplanes *and* computers. So I got into automatic computer guidance and control of aircraft and missiles." Jim does have a taste for expensive toys.

Before his accident, he had a bachelor's degree in aeronautical engineering from USC. After his accident, he went to school part-time (UCLA, cheaper and more accessible) and worked part-time on his guidance systems.

"When I graduated with a master's in computer systems engineering, I moved up here. I finally left aircraft when I came to the Lawrence Livermore Laboratory and started into computers on a full-time basis. I'm a principal computer scientist for the Computer Operations Division. Currently, I'm developing a network of intelligent computer terminals. Each terminal is a mini-computer. And now I'm connecting very large CDC 7600 computers to those terminals, making the terminals control teletypes so that the terminals can talk to each other, talk to the main computers and put out graphic displays for the computer operator in real time."

Personally, I'm delighted that this is what Jim does. I can think of no happier scenario than all those little mini-computers chatting and giggling together like teenaged girls first discovering a party line, while big momma CDC 7600 proudly and patiently looks on. I had brought my usual prejudices with me, one of which was that anyone who worked for the Lawrence Livermore Lab necessarily dealt with blunt instruments of global destruction. Not entirely so. Jim, a man of conscience, likes his work and plans to enroll at Stanford next summer without leaving Livermore. To do this, it helps to be into computers and related communication technology.

"I'm planning on entering Stanford as a PhD candidate in computer design. My company is connected to a closed circuit TV network where you can take Stanford courses at work and effectively be in the classroom because there's two-way communication in real time. They broadcast the class over TV and you can sit in class and ask questions back and forth over the TV even as the instructor is giving the class at Stanford. You don't have to go over there except to buy books or use the library. You can get a large portion of the units for a degree right here."

Has your accident affected your employability? "It hasn't lessened *my* employability. Well, yeah, let's say maybe. Because there was a job where I felt that there was some discrimination going on. But since I have two strikes against me, I couldn't figure out which one it was. So I said to hell with it and got another job. I've never had any trouble holding on to a job. I'm good at what I do and that keeps them giving me raises and paying me."

Other interests? Friday, he's going to a wine and cheese party. The party is the Berkeley CIL's way of introducing area employers to new graduates of their Computer Training Project. Jim started the project.

Saturday, he's giving a seminar in jujitsu at a junior college in Santa Cruz. As people call him up to do seminars, he does them. He holds a green belt. He's an official timer for the Sports Car Club of America. He swims a lot. He's into music; way into it. He's into damn near everything. What about the future?

"I'm planning on being rich. I'm writing two books.

One book is a cookbook and the other a biography. The cookbook is coming along quite well. It's called *The Chicken Magician*: it's 100 ways to cook chicken. I'm on number 50 now. (Then, as a continuing thought…) I'm buying a new Porsche."

What made you think you were going to be rich?

"Well, I've been planning on being rich for a long time. For a *long* time, ever since I was a kid. I'm not rich, but I'm workin' on it."

His advice to new injuries?

"People in wheelchairs are just too heavy on being people in wheelchairs. Really! I think that any person, regardless of what his physical, economic or social status is, can improve that by just focussing on the positive things that they have inside of themselves, selling that to themselves, and then putting it out into the world. That works. It really does.

"If you go around saying that you can't, then you *can't*. But if you go around saying that you can, then eventually *maybe you might*."

6.16.2 John Schatzlein

In 1963, John was 15. He was a jock, outdoorsy by nature, and fond of camping and wilderness. Tree climbing was one of the accepted ways most of us outdoorsy kids increased our appreciation of our surroundings, and John had the misfortune to fall 50 feet out of a tree. He broke his back on a limb part way down, and continued his descent as a T5 para.

Rehab: University of Minnesota Rehabilitation Department, his subsequent employer. Seven months.

School: "I went through high school and I was fortunate. My high school was on the level, so there was no question about going to it. And with 1,300 AB's around, I just became one of them. The disability really didn't interfere with much of anything that I did. That was a big catalyst to come back and just be a part of what was happening."

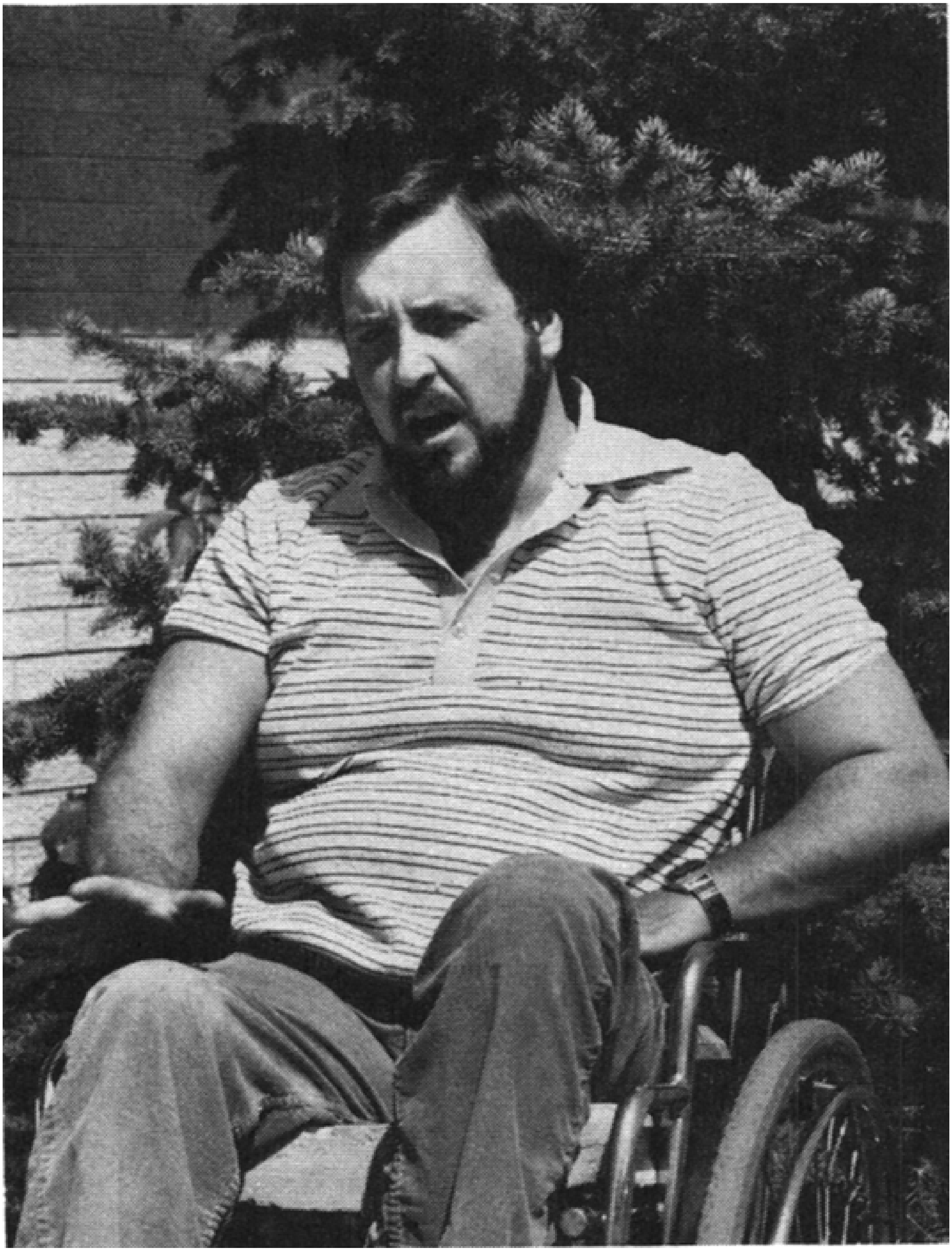
College: Southwest University, in Marshall, Minnesota. DVR helped. Again, there were no real problems. He graduated with a bachelor's in psychology and sociology and was president of the student body. "There really wasn't a question about whether I was disabled or wasn't. At the same time, I had met a woman who was an able bodied gal there and that kind of capped it all for me. Once I found the person that was important for me and she accepted me just as another person, another male, from that time on, in '67, I've never thought of myself as disabled. When that happened, it was just like, Well—I guess I'm whole. I'm normal. I'm average. I'm a little short and I can't walk. That was my wife. We got married when we were seniors in college, and that's almost 10 years ago already. Wow." It should be added that John and Helen have one child and are hoping for another.

Work: Generally, since the specifics. boggle the mind, John works part-time in public health for the University of Minnesota Rehab Center and part-time on his master's degree. Again very generally, he works on community resources, one-to-one counseling and teaching. Call him a rehab teacher, counselor and researcher, and you've got about half of it. He does more than that, partly because he *needs* to work. Except to tree surgeons, benefits and settlements are seldom paid for falling from trees.

So John augments his income and his professional stature by giving lectures around the country. Sexuality and Disability, for instance, and "I do a body image/self-esteem slide program that's an educational thing, trying to get people to understand where they begin to develop their image and self-esteem. And why does it change, if there's a traumatic or congenital disability, so that at 13 or 14 you recognize difference and begin to dislike yourself? It's been well enough received that I travel all over the country doing these for nursing association groups and OT and PT schools."

He also lectures and counsels on re-entry problems:

"The re-entry process is the responsibility of the consumer. It's not the responsibility of the rehab professional to force the person back into the community. It's the responsibility of the individual to put himself together, recognize that he is OK, and then go in and do it. The barriers are obvious. The physical barriers are there, the attitudinal barriers are still rather evident, but I think the re-entry process will get better as more and more disabled consumers go into the community and actually become part of it. The ease or the discomfort is resolved by more people seeing more disabled folks functioning just as everyday people."



Recreation: “I’ve been camping a lot since the injury. We’ve done tent camping and wilderness camping because modern conveniences just don’t hit it off with my wife and I. So we’ve done some northern Minnesota stuff, up in the

Boundary Waters Canoe Area and with the Outward Bound school. We put together a wilderness exploring kind of thing using the standard Outward Bound model as the thing that we wanted to try to duplicate with the disabled."

The result was that the Minnesota Outward Bound School cooperated with John and his colleagues to provide 10 day wilderness courses for people with a variety of disabilities. "We met and decided that yeah, this could be a unique experience that would stress people to the limits of their physical capacity, at the same time showing them that they could survive in a wilderness area. Consequently, our theory was, it meant that they could survive in the community. They could survive back in their home environments."

John admits that the tools don't exist to convincingly test his theory. He does know that disabled people survive the course. "We just got a group of guinea pigs together. We tried it the first time and found out that we'd survived, that we'd pulled it off. And then we developed the program from there."

A typical 10 day course might run like this:

- The first three days are in camp, except that camp is on an island, so you have to negotiate a path and paddle a canoe to get there. Basic skills with ropes, canoes and rough terrain are taught.
- The next five days are a land/water trek in the woods. Canoes, portages and some rock climbing, all done with minimal help from AB's in the group which might include an amputee, a SCI, someone who is sight- or hearing-impaired or with MS. During this period each participant does a one day solo, meaning you are left alone on an island or a peninsula to deal with yourself for a full 24 to 30 hours.
- Return to camp. Marathon. You commit yourself to a certain distance over a certain route, all of your own choosing, and it's your responsibility to meet your own expectations.
- Not surprisingly, a farewell blast. A party.

Information on the course is available from:

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Minnesota Outward Bound School
308 Walker Avenue South
Wayzata, MN 55391
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Here's John Galland's reaction to the course: "I was so high when I got back, I was just obnoxious."

And here's a little discussion on motivation and acceptance. Back to John Schatzlein:

"I think all people have the innate ability to be motivated. And I think that comes along at a certain individual's time line. I think there's a one to five year time line on the adjustment process."

That's exactly what a new injury doesn't want to hear.

"That's right. No way. We can speed it up to some degree, but people have to take their time. Some people may outwardly look adjusted, but if you talk to them five years later, they say, Yup, it was only about a year or two ago that I put it all together. Because we can fake what we look like on the outside."

I wonder if after *10* years, you ask the same person, he might say Yup, it was only last year that I got it put together *for sure*. I thought I had it at five years, but I didn't.

"I don't think that you ever do totally. I think you continue to progress. I don't think anybody ever 100% accepts, and I don't think that should ever be asked of people. Do you accept your disability? I think the honest answer is No. And yet most of us aren't ever going to say that."

I will. I know others who will.

"Hell, of course you don't accept it. You live with it, you cope with it and you do what you can to maximize your skills. But that doesn't mean you accept it. For me, I have just developed a high level of coping. I can deal with whatever the negative ramifications of the disability are because all of us, as humans, have the ability to cope with stress. Those of us who are identified as Those Who Make It have learned how to cope well and not let it interfere with the rest of their lifestyle."

That's grittier talk than I sometimes let slip through my ever-inspirational grasp, but it's also a real message of hope. Nobody likes the prospect of taking years to put a life back in order, yet it beats calling yourself a failure because you didn't do it in a month. AB's, too, take years to recover from setbacks, and the recovery period isn't a cessation of living or growth. It is life and growth. Your injury hasn't changed things all that much; it's just made your goals more clear. See?

6.16.3 Binny Clark

Binny Clark is not one of the new friends I discovered during my search for gimped America, but is an old and dear pal. A crony. We were brought together by a mutual need to make some sense out of messy lives. The focus of our interest was Chogyam Trungpa, Rinpoche, Tibetan teacher and founder of Buddhist meditation centers throughout the country. Rinpoche was a powerful and energizing force for both of us and dominated our lives for some time.

As the years went by, Binny moved into the heart of Rinpoche's Buddhist community and I became a dropout. We still check each other out as often as possible, mainly to see what craziness the other has gotten into now.

You're doing prostrations? Isn't that kind of —uh —trippy? "It's not as dumb as floating down rivers upside down in a kayak. And what about that Don Juan piece you wrote for Mountain Gazette? You going to do somersaults down waterfalls?" Beats wheeling.

And so on. For the purposes of this interview, Binny has agreed to omit (almost) all Sanscrit, freaky images and exotic practices which might make him sound like a religious nut. He's not. He's embarked on a long journey and has undertaken it with all the sincerity, good humor and commitment at his disposal.

So that you have some inkling of the journey's present coordinates, Binny is now, and has been for two years, the liaison between Rinpoche's headquarters in Colorado and his regional meditation group in Boston. Binny is the resident meditation teacher of over 100 Boston members, and both administers to and administrates his enclave.

Necessary details: Rolled a jeep in 1961, when he was 16. T11, spent one year in rehab near his home in New Hampshire. Graduated with his high school class, went to Dartmouth for two years, transferred to the University of Illinois at Champaign, won a Woodrow Wilson Fellowship and graduated with an MA in English and no desire to put his degree to use. “I got through the year and just fizzled.”

He lived at home for a year, then went to California during the flower child days. “I smoked a lot of grass and wasn’t getting much of anywhere. I put a lot of time into playing music and writing songs, sang in cafes; the normal route of a folky-type musician.” Things started going sour. “I became aware that I was doing it for uncomfortable reasons. It was a way of plugging my energy into something so I wouldn’t have to really look at the way the rest of my life was going, the idea being that if you make it as an artist, the rest of the 360 degrees of your personality doesn’t have to matter too much.

“I got an audition at Columbia, which I suppose for most musicians would be the light at the end of the tunnel, but for me it was the signal that I had to get serious about it or change directions right then. It wasn’t really working and I knew it at that point. It wasn’t the way I wanted to spend my life.

“During that same period, when grass and music began to run out as a way of stringing day to day, I’d been reading all this sort of hip literature —the drug literature, of course, has a lot of pseudo-spirituality involved with it —but in reading about these various spiritual quests, there was a great deal of trippiness. Instant enlightenment schemes. Kentucky Fried Nirvana. The more you looked into them, the more silly they looked.

“I did go around to various groups in California, and I guess the thing that finally impressed me that maybe something could be discovered through these various eastern religions that were trickling in at that time, was Ram Dass (aka Richard Alpert, Timothy Leary’s sidekick in LSD experimentation), who had just come back from India. He’d had a very strong experience at the time, and it was impressive that somebody could be quite that alive.”

Were you feeling unalive?

“Yeah, I think so.”

What sort of possibilities was Ram Dass talking about?

“That’s more difficult. I think it’s that there’s more to being human than the convention of plugging into the going culture of the day, living your life out and dying. And if you look at it, most cultures do say that.”

You had done some meditation before you met Rinpoche?

“Yeah, that was Ram Dass. My impulse, when I heard him that first time, was to follow part of his advice. He said the best way to meditate was to go off on retreat. So I went up to a mountain pass in Montana and camped out for three weeks — with mosquitoes, bears, a lack of water — but basically I had no idea of what meditation was. And for about a year after that, I tried various schemes. I’d read a book, and it would seem very good, and I would try it out for three weeks until I read the next book. Then I would try that. By the end of the year, I started getting negative hallucinations and various disturbing things and I knew then that I had to find somebody who had direct experience with meditation.

“Now I thought at this time that you had to go to the East to find someone who was genuine. So I thought —I’ll get a ticket and go to India — having no idea what I’d do when I got there. But then I got a brochure from Rinpoche’s meditation center in Vermont, so I went there. When I finally met Rinpoche, it was the first real, direct experience I’d had of meditation and spirituality being something that was very immediate and down to earth. Not exotic. It’s very well suited to the ways of this culture, even though it does progressively change the way you look at this culture.”

What attracted me to Rinpoche was that his *psychology* made sense. It had an enormous clarity and consistency with my experience. I never did see it as a religion, which you always said is why I became a defector. As I recall, you called me a schmuck. I was deeply hurt.

“Oh? It’s not a theistic set-up. It’s not looking to someplace else than the world. It doesn’t involve any kind of withdrawal from society; it actually revels in the juices that enliven and hold society together. Nothing is rejected in anybody’s psychology. Buddhism says it’s not a question of changing what your personality is at all. That means that there’s no embarrassment about anything that’s going on within your psyche. You can use positive or negative components of your personality as they are. Well, that’s very different from other philosophies and religions that I’ve looked at. There’s a kind of poverty in their thinking…”

… Out with the bad and in with the good?

"Right. Buddhism doesn't do that. It pushes everything back to the individual and says, *Look at who you are and learn to value that. It's much richer than you'd realized.*

"In my case, that was extremely important, because one of the problems of disability is the whole question of self-esteem. Who you are. That's the real crisis, because suddenly your whole idea of what you should be, your version of yourself, is changed radically. In everything I'd tried before there was that escapism quality of wanting to get some focus that would blot out the distressing, disagreeable areas of who I was. Meditation and Buddhism has been good for that because it says you *can't* reject that. If you try to de-emphasize the negative things and have this positive attitude in just one area of your personality or your life, the other part is bound eventually to catch up. This is fairly understandable in terms of western psychology. It's just repression. If you blot something out, eventually, it pokes its head out somewhere else.

"What it means to a disabled person is there's much more appreciation of who you are in the moment rather then what you are vis-à-vis social roles or social models. You're not as apt to be caught up in what society or Hollywood or Madison Avenue think you should be. You're much more apt to stay with who you actually are and to value that. It's a completely individual discovery. There's no real way you can communicate that out to other people except inasmuch as you seem to be on good terms with yourself. That does communicate.

"So gradually you find that you like yourself more. You're more friendly with yourself."

I've always liked that idea — making friends with yourself.

"It doesn't mean that you comfortably accept yourself with all your insecurities and paranoia. Making friends with yourself means that you can handle your life, that you don't have to be buffeted around by a kind of cramped view of who you are."

Well dammit, Binny, here we are all making friends with ourselves and developing a more accurate model of the world, but how come you're not becoming a contributing member of society by producing a lot of goods or services and paying a lot of taxes and making the system work better? Are you anti-American?

"What kind of interviewer are you? OK, that's a good point. The conventional view is that it's escapist, that it's turning one's back on the problems of the world, on the starving children in China, the boat people. The (Buddhist) idea is that you can't really begin to genuinely help the situation in the world as long as you're caught up in your own neurotic patterns. (In Buddhist teminology, Neurosis is something we all have and share. It denotes unclear perception of reality and its attendant behavior, and is thus less pejorative than western psychology's narrower use of the word.) The initial thing that has to start happening is that people have to stop polluting their environments in the sense of spreading their own neurotic view of things onto other people. Most of the ills in the world today come out of basically that. People are constantly pushing their trips on the rest of the world for all kinds of ideological and moralistic reasons.

"In this society, one of the main moral forces at work is the idea that everyone should conform to the American Dream, that the only way to be a healthy, whole person is to be part of the productive juggernaut."

What's this got to do with disability?

"People who are disabled have a very positive position. They can actually break loose from that whole insidious kind of pressure. It's because the fact of the disability is inescapable that the disabled person isn't as easily seduced into the whole *sleepy* view of what it is to be human. You can't be lulled into a kind of complacent acceptance."

Of other people's values?

"Sure. A lot of the standard assumptions of what it is to be a human being in the twentieth century in the West are based on fairly illusory value systems. I read somewhere that the average American sees or hears a thousand ads every day. There's a great deal of money spent to hold together the vision that this is the way to live. It's the good life. Grab for it. And for the disabled person, it's agonizing to see this consistently reiterated version of the successful man, the successful woman. If he takes the barrage (of media) seriously, a disabled person can't measure up to that."

Sure he can. He can earn a lot of money, he can buy everything that Madison Avenue is trying to sell him…

"Right. And when he looks at himself…"

… he'll feel just the way any intelligent able bodied American ought to feel. Shafted.

“Ok, but we have an infinite capacity to filter out disagreeable self-reflections. That’s why it’s so prevalent to have disabled people depend a lot on drugs and alcohol or personality quirks. You know, there’s the Cheerful Cripple who’s always happy or the Jock or the Completely Self-Reliant Proud Gimp…”

Or the Holier-Than-Thou Neo-Buddhist Gimp…

“That’s right. It could be. But the point is, you really do have to look very closely at what’s going on, because the filters go up almost without your realizing it. And suddenly you’ve created a personality for yourself which isn’t quite what you had in mind.

“It’s not just disabled people versus able bodied — every person who’s ever lived has had awkward moments when his roles suddenly fall apart and he’s left with this panicky feeling that he’s kidding himself. Meditation is the only thing that I’ve found that works directly with that kind of panic. The only way we can get that neurotic mess into the light of day is to actually stop and look at it, not just speeding on trying to maintain the pleasurable states. The idea of looking at it is not to rub our noses in our own shit, but just to find that that shitty area of our lives is fairly workable. We can handle it without having to freak out every time it pokes its head up.”

I’ve been thinking of becoming a Moonie. Do you think that would help?

“Depends.”

I’ve been thinking of changing from vodka to gin. Are you interested?

“Certainly.”

6.16.4 Hank Atkinson

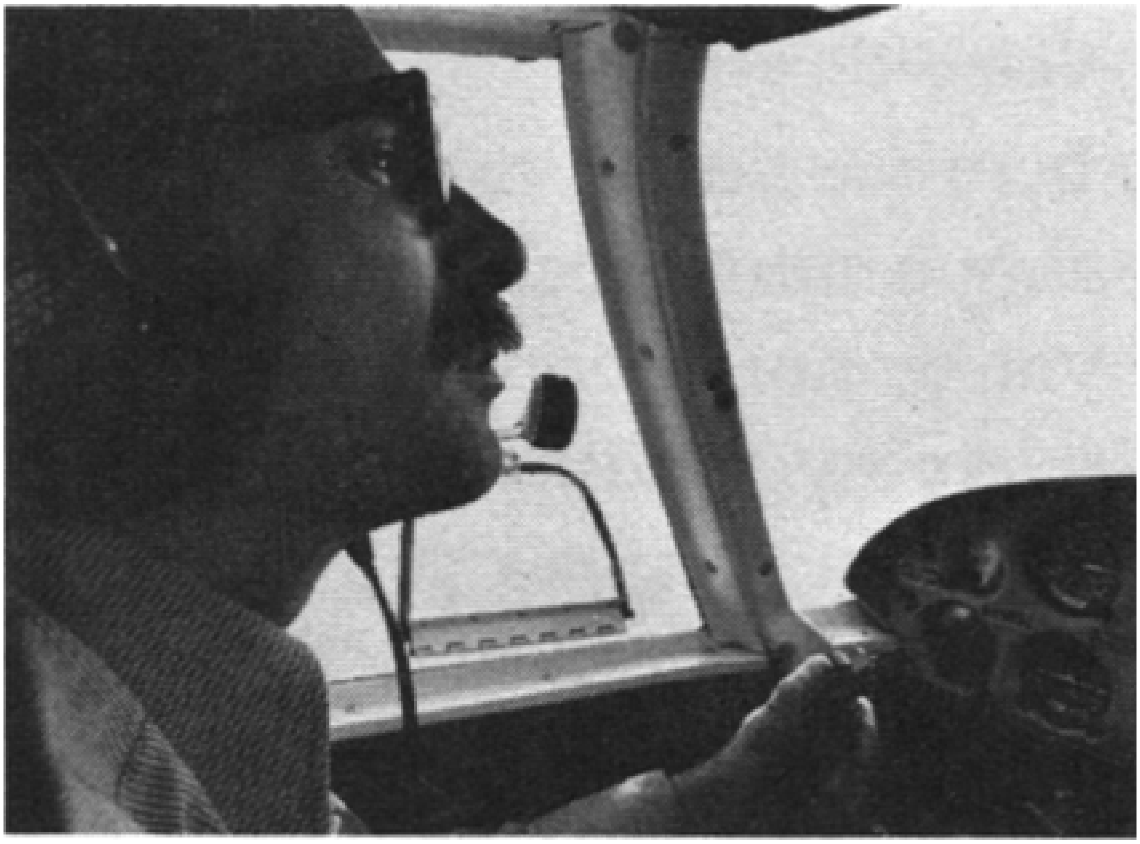
There’s nothing flashy about Hank except that he’s obviously alert and healthy and has a quick smile that somehow manages to spread slowly across his face. Got that? He looks as if he might be a computer technician, a stockroom manager or a teacher. He’s a geotechnical engineer and a T3,4 para from a car accident when he was 20.

Another thing. He’s been a para since 1959, and has *never* been hospitalized since then. Lots of experience here. Here are some of the things he has done:

- He resumed his education. “I was in the hospital for four months, got out, and I knew I was going back to school at the University of Illinois. But I had about three months that I spent at home. That period of time I really didn’t have much to do and that was a time of deep depression for me. Once I got back to school taking classes, I was so busy and so tired that I didn’t have time to be depressed about anything.” He emerged with a doctorate in civil engineering.
- He’s been appointed to the research faculty of the University of Colorado and has a private consulting practice on the side. His area of interest is underground coal mining and he’s widely recognized in the field.
- He flies a Piper Cherokee Arrow which he bought with some friends. The adaptive device is a simple lever mechanism which takes him five minutes to install or remove for the convenience of his co-owners. He does his own pre-flight from the chair. The wings are low, the transfer is a cinch and he can pull the chair in after him.

“In all the flying I’ve done, I’ve never had anyone say You can’t do it. They say, *Show* me you can do it.

“It’s really a freedom. I’ll fly to some airport, park the airplane and get out, and people really open their eyes and look, and say That’s neat, yet since I’ve flown up there and done it, they treat you like a pilot, with a professional sense of respect.”

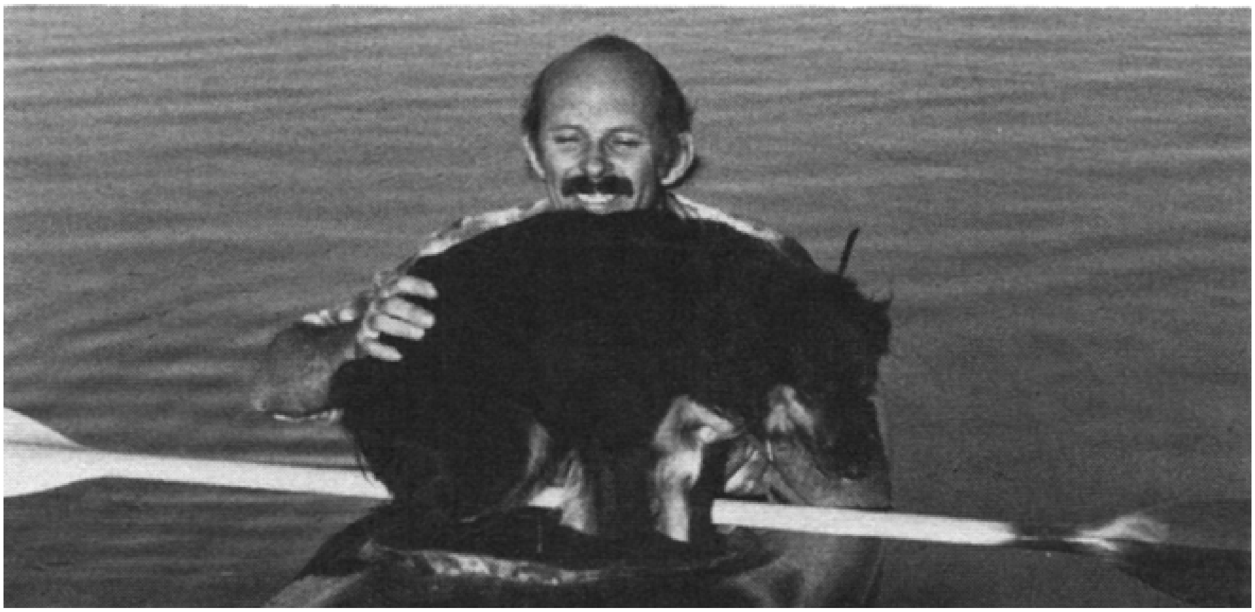


Hank works at his health. He swims three times a week, 600 yards each session; it keeps up his cardiovascular and pulmonary reserve and he enjoys it.

He's recently taken up kayaking and hopes to use the boat as a way to fish in seclusion on lakes where road access points are overcrowded. He's boated on two rivers now, rivers with real rapids, and has an expanded idea of what kind of water he's capable of running.

I asked him how, in dealing with new clients, he presented Hank-as-Hank instead of Hank-in-a-wheelchair: "Certainly people are surprised when they know the type of work I do, then see that I'm in a wheelchair. In a lot of cases you have to be the person who sets the tone of the meeting, be more assertive." He feels that many people experience initial discomfort with his chair, then promptly forget it. "The main thing is to have an aggressive attitude. That doesn't mean you have to be pushy in any sense of the word, but you have to go out and make things happen yourself."

And that quick smile is spreading slowly across his face right now. He's just unloaded his kayak from the roof of his Saab, wheeled it to the edge of a lake, and is getting ready to push off and make things happen. He's probably got a fishing rod stashed in his boat.



6.16.5 Bob McGinty

The day before the high school senior year began, the captain and star quarterback of the football team called a practice. It was a hot September day in New Jersey, so some of the team went to a local swimming hole to cool off after practice. The captain dove in, warned the others that it was shallow, then dove in again.

A few hours later, captain Bob McGinty was chatting with the doctors in the operating room, having rudely interrupted their ongoing discussion of what foods each had enjoyed for dinner. He told them that he had to be out in three weeks to make the first game of the season.

“I remember the doctor saying, Son, you’ve seen your last of playing football. It didn’t dawn on me at the time; what’s he know? I had a broken ankle when I was a kid, and it healed.”

And as the truth sank in: “It just seemed that my world came crashing down, because at that time I had no concept of what paralysis meant.” He knows now. He’s a C4,5, and his accident happened in 1956. He was 16 years old. Bob’s story, like many in this book, wouldn’t be likely to happen today. But in 1956, being a quad meant you had to be tough.

Bob’s “rehab” consisted of tongs, traction, a laminectomy and a Stryker Frame for six months. That’s all the hospital could do, so they sent him to a convalescent home in Delaware which was primarily an elderly care facility. He spent two years there and was discharged to his home. His parents bought a vacant house, modified it as necessary and took care of his attendant needs. Schooling seemed like the next logical step, which brought him to the State Department of Vocational Rehabilitation.

“When I was discharged after two and a half years in the hospital and I applied for assistance from Voc Rehab, they refused to give me that assistance because *I was too severely disabled*. And I accepted that, unfortunately, at that time.”

Thus began 10 years divided between two endeavors. The first was to convince Voc Rehab to accept him as a client and the second was to become an artist.

Becoming an artist was much the easier of the two. He took a correspondence course, started painting with a mouthstick and picked up some blue ribbons at art exhibits. The newspapers saw his work, featured him in print and Bob was able to sell paintings. It was never a real living, but it covered some expenses and gave him spending money. He painted all through the sixties.

And he battled Voc Rehab. For 10 years, they repeatedly turned down his requests for help in schooling. He had thought of going to art school.

“My first (DVR) counselor came to my house, looked at my paintings, and said Who the hell do you think you are, Van Gogh? It really shocked me that a rehabilitation counselor would say that. He said, Don’t you realize that artists are on every other corner selling their work for 50 cents? How do you expect to ever be independent by painting? This came from the agency whose whole responsibility is to further, assist and pursue employment for disabled people. He said, Why don’t you be realistic? The famous words, WHY DON’T YOU BE REALISTIC? You’re a cripple! You can’t do anything! Finally it dawned on me that the only way to get any assistance from them was for me to take the initiative.”

He did. He compiled extensive documentation of what other states did for their clients, then flooded Trenton, the state capitol, with facts and precedents. He made his own appointment with a psychologist, took a battery of aptitude tests and sent the results to Trenton. He talked to admissions directors at all the schools in his area to see where he could be accepted, and then let the state know about it.

“I kept telling these directors of admissions that I was coming as a student, and I didn’t know how I was getting there or how I was going to pay for it. So finally, I threatened Voc Rehab that I would picket the state capitol if they didn’t accept me as a client, and it seemed right after that, they said they’d give it a try.”

Ten years after first applying to Voc Rehab, he entered a two year community college. Once there, his grades generated scholarships and Voc Rehab paid for lunches, transportation assistance and adaptive equipment. He was class valedictorian the year he graduated.

Which brought up the possibility of an undergraduate degree. Voc Rehab agreed to stay with him, and he went to the University of Miami. There he raised hell, along with *Stephen Epstein* and others, and succeeded in making the campus almost completely accessible. He took a liberal arts program, earned more scholarships and graduated Magna Cum Laude.

Just as Voc Rehab was starting to relax, Bob decided to take the Law School Admission Test and was admitted to the University of Miami Law School. That sort of committed Bob to becoming a lawyer, which in turn committed Voc Rehab to pay expenses.

Whatever gave you the audacity to think you could become a lawyer?

“Stubbornness. I didn’t want to end up vegetating and looking at four walls. Life is too precious to do that. I have so much curiosity that I want to explore that I just wanted to break out and become involved in things outside my own mind.”

Bob was the first DVR client from New Jersey ever to receive graduate assistance. Had the agency people known just how long a ride they’d get taken on, they might have intensified their initial resistance. Yet Bob was becoming a feather in their corporate cap, and probably was starting to look pretty good to them.

Any law school is a den of obsession and cutthroat competition, and it wasn’t easy for Bob. Law students virtually live in the library, and he needed help just to get a book down from the shelf. But, “I figured I could always outwork able bodied students, because there were so many other activities they were involved in. It took me longer to do things, but I knew that that commitment had to be made if I was going to compete with them.”

In 1978, Bob passed his bar exam.

Then started the job search. “It seemed as if I had an easier time getting interviews than some of my classmates, but when I did appear for the interview, I was shown pretty condescending attitudes. They wanted to know if I could be a diligent, dependable worker. I think they thought of absenteeism, there would be times I wouldn’t be able to get to work, there would be transportation difficulties on some jobs —this was mainly in the private sector. I noticed a difference when I applied for jobs with government, or even in the judiciary system. They were very receptive.”

Bob decided to go to Washington, DC, since they do more government and judicial work there than most anywhere. His first interview was with the Small Business Administration, and they wanted him. He liked the people, liked the corporate and commercial law the job dealt with, and accepted outright.

In this day of Affirmative Action, he offers this candid observation: “I think my being a cripple is one of the factors they wanted. Maybe they wanted a showcase. They’re telling all the private companies and corporations that they have to hire the handicapped and they had to live by what they preached. But I think they were truly interested in me as a person. I think they were all aware, by the credentials on my resume, that they were getting a competent and dependable employee.”

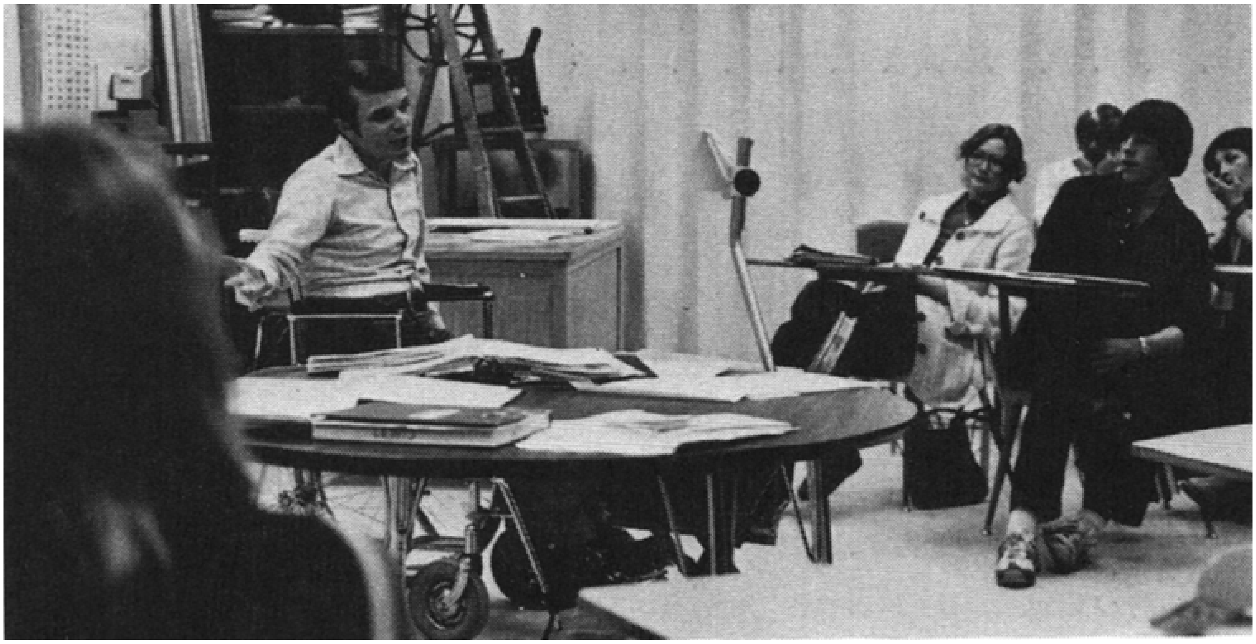
There’s still something wondering and childlike about Bob, as if he can’t believe where he’s come from and where he’s gotten to. He pauses briefly, his face does something between laughter and tears, and his happiness bursts out like sunshine: “After almost 23 years of being a quadriplegic, I’m now earning a living, I’m paying taxes, I’m off the public dole and it gives me great satisfaction. I see my prospects in the future are very bright, and I’m very satisfied with my position at this time.”

And he likes being Robert McGinty, Attorney at Law.

And he’s sincerely grateful to the New Jersey State Department of Vocational Rehabilitation.

6.16.6 Rob Lewis

In 1969, members of the National Honor Society thought so highly of one of their teachers that they presented him with the Teacher of the Year Award. For a serious young man named Rob Lewis, it was a recognition to be savored.



Rob’s a T7,8 para from a car accident in 1964. He was a college sophomore at the time. A year of rehabilitation and part-time studies later, he transferred to the University of Missouri, picked up a BS in Education, briefly attended law school before deciding that teaching was what he wanted to do, and returned to Missouri to complete his master’s degree in guidance and counseling.

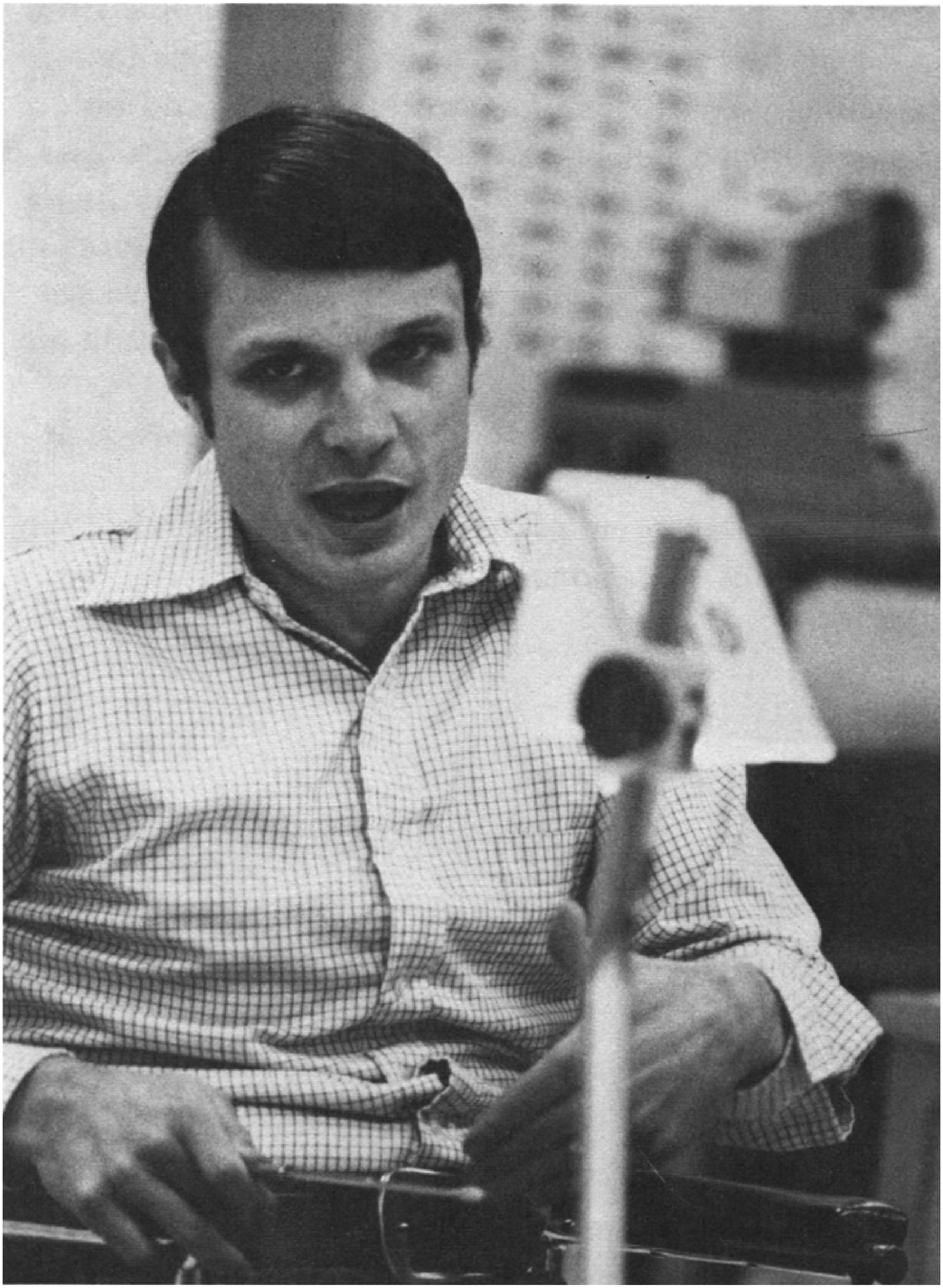
Rob's transition from schooling to working was typical of wheelers going on to higher education. Hank Atkinson, a para with a doctorate, compared extended schooling with preservation of "the safe haven of institutional protection." Rob didn't make that comparison, but there's something similar here:

"For a long time I was very hesitant to go to work, not because I disliked work, but because I enjoyed school and the easy life more. So I think that's one of the reasons I went to law school and went back for my graduate degree. And then I got to the point where I finally had to get a job."

It wasn't too tough. He was hired at the first school he applied to: "I encountered absolutely no resistance whatever. As long as I could perform my job, as long as I could communicate with students, that's the main thing."

It has obviously worked out well, for Rob's been at the same school for 10 years. About the time he started teaching, he married Riva; another relationship which has lasted. He has yet another relationship which he takes very seriously, that with his students: "I'm very obvious, of course, but I try to make a point the first day or two of class of telling them precisely how I got to be in the chair and letting them know that even so I'm a competent person, I'm married and I live a very normal life except that I have a few extra pieces of equipment I carry around with me. I think students are very readily able to accept that."

And after 10 years of teaching? He's taking his sabbatical this year; he'll use it to work in library media at the University of Colorado. But he'll be back. "The freedom being an educator gives me is that thing which I value more than anything else. I always come back to education. I enjoy the contact with students, I enjoy the caliber of people who work in that situation — other instructors —so I guess there is really not another job now that I would consider taking."



Since Rob teaches philosophy and psychology, I'll relay his word on motivation without comment: "There's no such thing as an unmotivated person. There are only persons who, for a period of time, reach a state where it seems that there's nothing that can be done. And that's very real. But I also see it as *not* the truth. Maybe it's like physical maturation. Some people bloom earlier than others, but they all bloom. I guess I would say that's what motivation is all about. It's just when it will occur; it's not *if* it will occur. It will occur. Sooner or later, the bad becomes better and one success leads to another. And another and another. The capability is there, and the will will come."

Now, in 1979, I've returned to a classroom for the first time in over 20 years to watch Rob teach. It's a relaxed setting; students wandering in, chatting with each other or with Rob, sitting where they want and looking pleased to be there. Rob starts winding up. His subject for today is sadism and masochism, and within a couple of minutes he has every student in the class confessing to acts of sadism in their lives. Rob clowns, cajoles, reasons and rages, and has the kids doing the same. He bludgeons them with words and logic and showmanship and their own participation. And all the time, he's moving all over the room. I'm taking pictures, and it's like covering a sports event. Fast and exciting. The students love it. Rob loves it. I love it.

6.16.7 Elmer Bartels

Remember the DVR guy that at least half the people in this book have bitched about? That guy who doles out benefits according to whimsy or rigid rules, but never according to human potential? That guy who sees every request for funding as creeping socialism and every success story as his own moral victory? That guy who doesn't want his clients' education to surpass his own? Well here he is. Elmer C. Bartels. He runs the Massachusetts Rehabilitation Commission. He is *the* Commissioner, or, in the language of the day, he is the State Director of Vocational Rehabilitation. The buck stops here.

And stop it does. In an hour and a half, this man spoke more sense about SCI, its pitfalls and opportunities, its history and future, than I've heard from any single source. His waters, as one of his friends remarked, run very deep. He seems like a good person to act as final spokesman for us all; our valedictorian.

Details: Hockey accident in 1960. He was 22 years old, a senior at Colby College in Maine. C4,5.

Rehabilitation: 12 months at two different Massachusetts hospitals, and one month at Rusk. He calls Rusk his finishing school: “The one thing they did for me at Rusk was to say, basically, You can do what you want to do and don’t let your disability stand in your way.”

One of the things he wanted to do was get married, which he did 13 months post-injury. He showed exceptionally good sense, in fact, by marrying one of the nurses he'd met during his recent tour of rehabilitation facilities along the eastern seaboard. He is still happily married and has two children.

1962: BS in physics, Colby College. 1964: MS in physics, Tufts University.

Then followed three careers. After graduation, he spent four years working in nuclear physics at Massachusetts Institute of Technology. MIT enamored him of computers, so he switched over to a second career at Honeywell Information Systems, manufacturers of computers. At Honeywell, he started as a senior systems analyst and was promoted to department manager. In January, 1977, he was appointed Commissioner of the Massachusetts Rehabilitation Commission.

Elmer's Vitae sheet is awesome. He is a founding father of the Massachusetts Association of Paraplegics and the New England SCI Foundation. He holds honorary doctorates from both Colby and Tufts, about a dozen awards honoring his work in SCI and rehabilitation, and has authored or co-authored articles, papers and monographs ranging from rehab-centered topics through *The Nature and Use of Conversion Software* and *The Design of an On-Line Computer Based Educational System for Industry* to *Analysis of Fragmented Analog-State Resonances by Coupled Optical Equations with Effective Nonlocal Potentials*. Enough?

So how did careers in nuclear physics and computer systems prepare him to run a thirty-five million dollar public agency? Elmer gives the credit to his promotion to department manager at Honeywell and to the person who took the risk of offering a high level quad that position. "It allowed me to develop management skills and perfect them to the point that coming to do this job was a viable thing to do. It made sense to me and to the state and to the governor who appointed me." It also made sense to the subsequent governor, who made a clean sweep of the existing state bureaucracy in 1979 but retained Elmer Bartels.

"During my whole career, I've had kind of an avocation in the area of SCI and developing systems of care, standards, resource documents and general improvement of the system as it impacts on the lives of people who have become SCId. So I have flipped from my computer career over into a rehabilitation career. My hobby is now computers and my work is rehabilitation.

"One of my priorities in running this agency is Consumer Involvement, developing a philosophy whereby the professionals in the agency and the clients served by the agency can work together on mutual issues — advocacy, quality assurance of this agency, policy considerations —just a whole host of things. The essence of it is, we can't do it alone. The job's too big; we've gotta do it together."

One of Elmer's on-the-job triumphs is the creation of a 100% state-funded program paying for personal care attendants. (To my knowledge, California is the only other state doing so.) To many quads, this benefit is the *sine qua non* of holding a job. The state is richly repaid through taxes the new employees pay and by gaining new contributing members.

On motivation: "Some of it is the lifestyle people bring to an injury. People who are accomplishment-oriented tend to do well. People who are not accomplishment-oriented tend to not do so well. But that's not the whole story. If you take someone who is accomplishment-oriented, and you don't provide a light at the end of the tunnel and provide a perspective of what they can achieve providing they attempt it, if they can't see where they're gonna get, then they won't try to get there. But if they can *see* it, they'll go get it."

And for the non-accomplishment-oriented?

"That's where the creativity comes in; it's sort of a step-by-step process of becoming successful almost in spite of themselves. But that's a gradual approach, setting short-term objectives. They have to be given intermediate goals that they can achieve in order to reach for the next step. And that is the motivator: having accomplished once, people will attempt to accomplish again. And again and again and again, if the steps are small enough."

Some people seem to just stay devastated by their disabilities.

"Some of them, the system has failed them in providing the goal-orientation, the gradual successes along the way. And they've been booted in the pants so much that their emotional elasticity is gone. They've met with failure after failure after failure. For instance, someone gets pressure sores from day one, which is medically inexcusable, and that issue comes back to haunt him again and again and again. Every time they get up in their chair and begin to get going, the pressure sore issue comes back again. That could have been prevented by proper medical care, and the physicians that allow it to happen should be sued. They're not. They should be. It happens too often, even in our advanced SCI systems. Another issue might be bladder infections, where improper bladder care has occurred from day one and comes back again and again and again. Those things are imposed by error, so the system has failed them.

“And there’s another side of it. That is the benefits issue, and I see this more in terms of the VA. For the service-connected injured, they have a benefits structure that will pay them up to twelve or thirteen thousand dollars a year, buy them a car and buy them a house. They’re *nuts* if they go to work. And what do they do with their free time? They drink, they sit around all day and they slowly deteriorate. They’re killing themselves. So the VA, by its benefits structure, is forcing people to live in a dependent fashion. If they’d cut the benefits out on a gradual withdrawal basis, and put some incentives in the system, that would be helpful. That’s also true of SSI and SSDI.”

How about kids who never did want a higher education, who just wanted to finish high school and join the work force and have some loose change in their jeans?

“People without high school diplomas have developed businesses as a stock broker or started a mailing business —it depends on how much you are motivated to accomplish. Just because you happen to be a C6 quad doesn’t mean that that’s the end of productive living. It’s merely the beginning of productive living, only in a little bit different form than you might have thought. And it may, in fact, be a better quality life in the sense that instead of living in the army for 20 years and then going on retirement, you may be more productive in terms of contribution to yourself and society.”

Elmer is well pleased with legislative progress over the last 20 years, especially that affecting architectural barriers, services to the disabled, education and civil rights.

"I think there's enough structure there, from a legal perspective, that we don't really need that much more. We've got enough of a legal sledge hammer to get people's attention. The issue now is getting at attitudes, and the only people who are going to change attitudes are the disabled as they take positions of leadership in the community. People have to get out and take their own *personal responsibility* to change the attitudes of people around them. If you take that and build on it — that every individual that is disabled is indoctrinating society —it will do the job in 10, 20, 30 years. Because there are more disabled people, with more friends, more people they come in contact with, and more attitudes get changed. That's what I see will happen over the next 30 years. And we'll look back, 30 years from now, and say this was the Dark Ages with respect to attitudes toward handicapped people."

Love your chair? Hate your chair? Elmer, as usual, aims at the dread heart of the matter: "Living in a wheelchair for the rest of your life is not significantly problematic. People in wheelchairs work, they get married, they have families, they do a lot of things. *Living on wheels becomes a non-issue*. It's a damn nuisance and that's the extent of it. And you can do what you damn well please."

6.17 The Last Hot Tip…

Final Admonishment…

And Parting Shot…

> We crystallize for ourselves and for others the real fact and fear of calamity. If we reinforce this image, we invite sympathy and sorrow. If we proceed apace, we are inspirations to everyone. We should not be afraid to inspire—the world needs it badly and we need the experience of giving extravagantly. Our gift to the world is the world's gift to us. Everybody, able bodied and disabled alike, should take the money and run.
>
> —Barry Corbet, Lookout Mountain, Colorado, 1980

CHAPTER

SEVEN

PART 3: SELECTED BIBLIOGRAPHY

7.1 References Categories

While I tried to read as many relevant books as possible, I make no claim to having exhausted the literature. There are undoubtedly many fine books that I just plain missed. Others are omitted because they're bad. I feel that the books commented upon below are of interest to at least some SCI's. They are not all works of artistic or scientific splendor.

Books and periodicals relevant to SCI seem to fall roughly into four categories:

A. Medical, of interest to doctors and extremely dedicated technicality-buffs. One reason that doctors are well paid is that they had to wade through all this stuff. Ask your doctor for the information or for specific references.

B. Research reports, primarily produced by health professionals for health professionals. Usually dry stuff, dropping statistics like dandruff, but there are some nice surprises.

C. Information books, magazines and pamphlets written specifically for the disabled, often by the disabled. This category contains the biggest slug of useful information for a newly disabled person.

D. Books written by the disabled, or as told by the disabled, for the general public. Since these books are designed to sell, they tend to dwell on hardship and pain and their eventual overthrow by discipline, diligence, divinity or indomitable courage. They sometimes inspire the public and depress the disabled, but there are exceptions.

An A, B, C or D following the title indicates the category into which it most readily falls.

Accent on Living, *Buyer's Guide* (C), Cheever Publications, Bloomington, Illinois, 1977. Revised annually. If you know what you want but don't know where to find it, this booklet may help. On the other hand, you may resent paying for a book which is over 50% advertising.

Baxter, Robert T., *Salvaging Our Sexuality* (C), Medical Media Visuals, East Orange, New Jersey, 1979. An excellent little book by a quad. Honest, unpretentious, not too clinical, admirably protective of women's sensibilities and realistic throughout. A fine contribution.

Bowe, Frank, *Handicapping America* (C), Harper & Row, 1978. A well-informed cry of outrage; sweeping ideals of slow change, but few ready solutions. Overlaps into categories (B) and (D).

Bregman, Sue, *Sexuality and the Spinal Cord Injured Woman* (C), California State Department of Rehabilitation, Inglewood District, 1975. A helpful and simple booklet from a woman's point of view.

Brickner, Richard P., *My Second Twenty Years* (D), Basic Books, New York, 1976. An excellent writer chronicles his twenty years as a quadriparetic. Sometimes humorless, often obsessed with his re-entry to the sexual arena, this is an intelligent book which makes thumping contact frequently.

Bruck, Lilly, Access: *The Guide to a Better Life for Disabled Americans* (C), Random House, New York, 1978. The finest compendium of hints and facts that I have found. Well organized, lively and full of heart. This is a fine reference book for all aspects of disability.

Cheever Publishing, *Accent on Living* (C). Quarterly magazine, perhaps the best periodical review of new ideas, equipment, legislation and developments of interest to all disabilities. Slick it's not. Accent also runs a computerized information retrieval system called Accent on Information and has published several booklets of varying worth on various aspects of disability.

Cheever, Raymond, C., *Bowel Management Programs* (C), Accent Press, Bloomington, Illinois, 1975. A down-to-earth how-to-do-it book.

Cheever, Raymond C., *Home Operated Business Opportunities for the Disabled* (C), Accent Press, Bloomington, Illinois, 1977. How to make pauper's wages at boring jobs. Perhaps of interest to those who want part-time work or need to stay under Social Security Gainful Employment maximums.

Crase, Clifford and Nancy, *Sports 'n Spokes* (C), bimonthly magazine dedicated exclusively to wheelchair sports.

Crewe, Nancy M., et. al., *Employment After Spinal Cord Injury: A Handbook for Counselors* (B), University of Minnesota, Minneapolis, 1978. Not just for the pro's. The first section is an excellent synthesis of employment problems and solutions, the second consists of 79 short biographies of working wheelers, with an emphasis on quads, and the last is an index of professions suitable for the severely disabled.

Dickey, Imogene, *Recipes and Cooking Hints for Brides and Other Handicapped People* (C), Imogene Dickey, 950 N. Carrington, Buffalo, Wyoming, 1978. Down-home cooking made easy for anyone. This friendly book by a quad (see *Imogene Dickey*) is just what the title says it is.

Eareckson, Joni, *Joni* (D), Zondervan Publishing House, Grand Rapids, Michigan, 1976. A squeaky-clean, widely-read autobiography of a young quadriplegic woman who learned to have a terrible time and praise the Lord. Of genuine interest to Christian witness devotees.

Epstein, June, *Mermaid on Wheels* (D), Ure Smith Pty Ltd, Sydney, 1967. The story of an Australian paraplegic woman's accomplishments, this book will inspire only those whose most fervent desire is to become a housewife and mother.

Fallon, Bernadette, *So You're Paralyzed…* (C), Spinal Injuries Association. London, 1975. A British woman has written a no-nonsense book of information on SCI and how to cope with it. This may be the best survey course in paralysis yet written for new injuries. Not bad for TAB's, either.

Gregory, Martha Feguson. *Sexual Adjustment: A Guide for the Spinal Cord Injured* (C), Accent Press, Bloomington, Illinois, 1974. Pretty good, but a little obsolete. If you've read Trieschmann, you'll have trouble believing some of this.

Goldenson, Robert M., et. al., *Disability and Rehabilitation Handbook* (B), McGraw-Hill, 1978. An encyclopedia. If you're becoming a counselor, therapist, social worker or an activist, read it. Otherwise…

Gollay, Elinor and Bennett, Alwina, *The College Guide for Students with Disabilities* (C), Westview Press, Boulder, Colorado, 1976. Another encyclopedia, this one detailing accessibility, number of disabled students, policies, services, programs and community resources at hundreds of colleges and universities. Excellent if kept updated.

Hermann, Anne Marie C., and Walker, Lucinda A., *Handbook of Employment Rights of the Handicapped: Sections 503 and 504 of the Rehabilitation Act of 1973* (C), Regional Rehabilitation Research Institute on Attitudinal, Legal, and Leisure Barriers, Washington DC, 1978. The most comprehensive book extant on employment rights.

Laurie, Gini, *Housing and Home Services for the Disabled* (C), Harper & Row, Hagerstown, MD. Everything you need to know about architectural adaptation, attendant care, residential options and government-assisted projects. Aimed primarily at the health delivery services.

Marx, Joseph Lawrence, *Keep Trying* (C), Harper & Row, 1974. The title notwithstanding, this is a pretty warm comment on dealing with disability by a polio victim. Much good advice, and occasional good humor. You'd have to call it a *nice* book.

Mooney, Thomas O., et. al., *Sexual Options for Paraplegics and Quadriplegics* (C), Little, Brown and Company, Boston, 1975. A pretty good little how-to-do-it book, illustrated, which will be helpful to many and sexually sobering to some.

Nasaw, Johnathan Lewis, *Easy Walking* (D), Lippincott Company, 1975. Far and away the best of all books by a paraplegic. It's a little self-pitying at times, but consistently brilliant. Wait a year after injury to read this one; it won't make you feel lucky, but it will give expression to a lot of your frustrations. Quads will think this guy isn't hurt badly enough to take seriously. Stay with it for sure until you meet Cripple Willie. He is us.

National Paraplegia Foundation, *Employment Opportunities for the Spinal Cord Injured Person* (C), NPF, 1977. Good, but don't accept its list of occupations suitable for the motivated wheeler. It doesn't touch the real possibilities.

National Paraplegia Foundation, *How to Get Help if You Are Paralyzed* (C), NPF, rev. 1975. An excellent primer dealing with money sources, access to information, and how to tell if you're getting good care.

National Spinal Cord Injury Foundation, *National Resource Directory, 1979* (C), NSCIF, 1979. A superb gathering of practical information, much of it digested from other sources, but presented in an extremely useful format.

Paralyzed Veterans of America, *Paraplegia News* (C), a monthly organ of the PVA with information of interest to vets and non-vets alike.

Robinault, Isabel P., *Sex, Society and the Disabled* (B), Harper & Row, Hagerstown, Maryland, 1978. An exhaustive book, and exhausting. It's quite good, done with a fairly light touch, and may intrigue inquisitive readers. Mainly for professionals. For a quicker read, try *Accent's Sexual Adjustment: A Guide for the SCId.*

Roger, Michael A., *Paraplegia* (C), Faber and Faber, Boston, 1978. A hardcore how-to-do-it from a Terribly British Tetraplegic. Practical advice for keeping a damaged body healthy. Humorless and helpful.

Segal, Patrick, *L'Homme Qui Marchait dans sa Téte* (D), Flammerion, France, 1977. Another intelligent book, now available in English. A paraplegic photojournalist travels the world. Full of pride and life and love.

Strebel, Miriam Bower, *Adaptations and Techniques for the Disabled Homemaker* (C), Sister Kenny Institute, Minneapolis, Minnesota, 1973. Probably the best of the breed. Real solutions, well illustrated.

Trieschmann, Roberta B., *Psychological, Social, and Vocational Adjustment in Spinal Cord Injury: A Strategy for Future Research* (B), Easter Seal Society, Los Angeles, California, 1978. A monumental review of over 350 books, articles and research projects relating to SCI which delivers the newest and best state-of-the-art condensation in print. Trieschmann is a concerned, impartial, thorough and aggressive researcher who pokes holes in a lot of sacred cows. An important book for those who want a scholarly digest of what SCI has meant for large numbers of people studied under many disciplines. Caveat: the Behaviorist paradigm predominates. Excellent.

Valens, E.G., *The Other Side of the Mountain* (former title, A Long Way Up) (D), Warner Books, Inc., New York, 1975. The classic story of Jill Kinmont, ski racer turned quad and teacher and survivor. A great nostalgia piece for elderly ex-skiers like me, but understandably dated.

Weiss, Louise, *Access to the World: A Travel Guide for the Handicapped* (C), Chatham Square Press, 1977. A knowledgeable collection of hints and haunts for the handicapped, with emphasis on the wheelchair user. How to deal with planes, trains, buses, cars, hotels, tours, agents and your health. Plus destination and accessibility guides. Good.

7.2 Acknowledgment

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CHAPTER EIGHT

BACK COVER

8.1 Reviews for Options

OPTIONS is must reading for all spinal cord injured persons when the time comes to make their decision — some early, some late —"'What am I going to do with the rest of my life?" Rehabilitation professionals, regardless of their level of expertise and experience, have a major handicap in understanding the desires and despairs of their "patients." *They haven't been there!* This book provides an intimate glimpse beneath the surface. This is where the action is. Rehabilitation is a people business and you have to know the territory.

—From the foreword by John S. Young, MD, Spinal Cord Injury Doctor

This work is important reading for everyone who likes to contemplate the magnificence of the human spirit faced with adversity. It is absolutely essential to the spinal cord injured, their families and friends, and the professionals who provide their care. It is especially crucial for the isolated spinal cord injured who do not have treatment and rehabilitation in a good Spinal Cord Injury Center and are thus deprived of models for successful living with a disability. A powerful and moving contribution by "gimps" for "gimps" —and everyone else.

—George Hohmann, Ph.D, Professor, University of Arizona

OPTIONS serves a very worthy purpose for persons who have experienced spinal cord injuries, especially those individuals who have been recently injured. The interviews present a variety of perspectives from other people who have suffered the catastrophic consequences of trauma to their spinal cords. It is a positive approach to assisting in the process of adjustment, rehabilitation and coping.

—Bruce E. Marquis, Executive Director, National Spinal Cord Injury Foundation

While immeasurably improving life saving skills over the last 30 years, we have, in my experience, done a lesser job of answering the question: *survival for what?* There have been increasing numbers of publications and books written by physicians directed at physicians, by therapists directed at therapists and by various other persons; all talking *about* but not *to* spinal man. Here, at last, is a book that is by, of and for the spinal cord injured population, as well as for *all* health professionals who work with spinal cord injured people. It is an enlightening, humbling and exciting experience.

—Robert R. Jackson, MD

8.2 The Author

Barry Corbet, prior to a helicopter accident in 1968, was a mountaineer, skier, film maker, hotelier, shop keeper, father and severely able bodied person. He is now a kayaker, film maker, author, muck raker, father and paraplegic. He lives in the foothills of the Colorado Rockies.

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