

# MATRIX OF A SOCIAL SPASTIC

BY ARTHUR HONEYMAN

Arthur Honeyman, one of the most famous and notorious Oregonians in the state's history, is 65 on May 10. He has spent his life fighting for the rights and recognition of people who are considered "physically handicapped." He is a teacher, poet and writer, author of the award winning "Sam & His Cart" and several other books, essays and collections of his poetry. He is co-founder of Wheel Press. He has a Bachelor of Science Degree in History and a Master of Arts in English, both from Portland State University.

Cerebral Palsy is perhaps one of the worst afflictions that can strike a person. Because I am a victim of this affliction, much of what I am writing centers around me. What I write is what I have observed from self experience and from others who are also handicapped by cerebral palsy. I write not only about the physical problems of the cerebral palsied, but also show psychological problems a cerebral palsy victim suffers.

I do not intend a long and technical analysis, which I myself do not understand and cannot even hope to explain. I will satisfy myself by barely touching the definition and the causes of this affliction. Because cerebral palsy is not a disease and because most cerebral palsied victims have internal organs which function normally, the average CP has no real health problems. For instance, I am rarely sick enough to stay in bed.

Most of the literature which is written on cerebral palsy concerns the care of children stricken by it. I will try to restrict myself to the problems of the teenager and the young adult.

Cerebral palsy is also known as *Little's disease*. Doctor Little was probably the pioneer in medical interest in what is commonly known as palsy, or spasticity. The number of victims of cerebral palsy is estimated at various numbers. One book says there are 400,000 CPs in the United States, while another says there 550,000. About 200,000 of these are children and 350,000 are adults. It had also been estimated that every 53 minutes a child is born with cerebral palsy.

Cerebral palsy is, of course, due to brain damage, probably to the medulla and cerebellum. Some injuries are prenatal, others parnatal, and others postnatal.

Prenatal damage is generally due to two types of injuries — either hereditary or congenital. Tuberos sclerosis and *tay-sacks disease* fall under the first cause. Anoxia, maternal infections, metabolic disease and RH factors fall under the latter cause.

Cerebral palsy due to parnatal (during birth) is generally caused by mechanical damage such as trauma. This includes squeezing the brain too hard during labor or by forceps in the process of delivery. Also there are prematurities, low vitamin K level, and anoxia. Parnatal also includes asphyxia which is due to respiratory obstructions during labor.

Postnatal refers to brain damage after birth. Such injuries as skull fractures and wounds come under trauma which is usually brought about by falling on the head or by similar accidents. The second is infectious which is caused by meningitis and encephalitis. Third is vascular by hemorrhage, thrombosis and embolus. Anoxia is caused by carbon dioxide and/or monoxide poisoning and neoplasms.

There are several types of cerebral palsy. There is spasticity which is usually characterized by short jerks or rhythmic spasms. *Athetosis* refers to a type of cerebral palsy in which the victim makes twisting wormlike motions. This is the type I suffer.

More often than not spasticity and *athetosis* are intermingled.

The third type is *ataxia* which refers to slow, stiff, almost paralyzed movements in which walking is difficult. There is a sense of anti-gravity and the victim often has a reduced sense of balance. Other characteristics are flabby and loose muscles.

The fourth is rigidity which is characterized by stiffness. The victim finds it difficult to move limbs and motion resembles an unoled robot.

Tremor is the fifth type and is characterized by involuntary rhythmic movements. In some victims, not only may their muscles be uncoordinated but the senses may be haywire.



## SPASTIC FOR AN HOUR

BY MICHAEL McCUSKER

The night I pretended I was a cripple was Michael Marsh's birthday and the big shaggy cantankerous moonfaced bear was getting juiced on red wine. Arthur Honeyman was drinking wine through a straw and for all I know I might have been lapping wine up from the table.

Halfway into the time most people eat dinner and scramble their digestion with the evening news, Arthur held a quivering hand in the smoky air and asked if I would take his 'Spastic Power' walking cart to Konina House (near Portland State University, which he was attending for a Master's Degree in Literary Arts). He would probably get somebody to drive him along later.

I fell out into the foggy night and climbed into the cart the way Arthur does and the first thing I learned was I don't have leg muscles anymore. After several years hauling himself around in that cart, if he got close enough, I'm sure Arthur could bring a bull down with one kick.

The next thing I learned was why he is so self-contained, so complete a person. He lives in a shell he didn't build, forcing him to develop fully within himself. Others built the shell for him before he got a chance to do it himself, like most of us do. They built it because they were afraid and some of those Others who walk around freely not even thinking about the intricate complexity of the bio/machine programming the lifting of a foot, the bending of a knee, did their best to use the machine in getting around me.

Bent over, hanging onto the iron bars of the cart, pulling with two out-of-shape legs in short, choppy steps, I was a freak to the NORMS scrambling past. They couldn't look at me or touch me — lightning would shoot out of the sky and make them freaks like me; I was a leper and my flaking skin would infect them; I was a disease they had to shut out because it wasn't their fault they could walk and I had to shuffle along in a cart, and Jesus Christ, there were enough things to feel guilty about these days — the (Vietnam) War, Bigotry, Poverty, Pollution — without torturing the weary giddy brain with one more burden on the sanity.

They walked past, seeing me (they couldn't help seeing me, but they didn't want me to know they saw me) as they walked past, if they walked past, because several of them veered off, crossing the street or stopping and turning their backs to me until I struggled out of sight, and it doesn't matter what reasons they had, if they were aware of them, what did matter was how I took their avoidance and maybe Arthur doesn't let it bother him anymore, if he can cork his emotions — but I was Arthur Honeyman For A Day (an Hour really), a big liberal trip, an idea that came with several red wines, but you learn in any way that you can, however impoverished the chances, and though I can't shake my body like four winds tearing at a tree, the contortions Arthur has to put up with from his body, I could take a walk one foggy night in an iron-barred box with shopping cart wheels and let everybody pity me as a cripple and solemnly think, 'There but for the grace of God....'

I started asking for help. Give me a little push, will ya, huh? "I'm going the other way," a man said. "Sorry but I've got to meet somebody," apologized another. A woman was in a hurry, a man was just going up to his room, another was just going to his car — everybody had a good reason not to give me a push in my funny-looking cart. They didn't sneer, nor were they in any way hostile (you oughta be grateful you weren't pushed over a cliff like they used to do with cripples); these people were really well meaning and apologetic, if not embarrassed at not knowing what to do or say. They simply didn't want to get involved with me to even that minor extent because it goaded a greater responsibility and it was just more convenient to chastise themselves with the guilt of having done nothing than to do something and realize the responsibility for brothers and sisters does not end with token gestures of goodwill, it demands every breathing moment of every person's life.

The guilt is easier by a long shot; if you've made it this far without freaking out or cracking up, you know damn well your defenses are in pretty good shape — I am certain the crippled man in the beat-up little cart would have been quickly forgotten by protective minds except:

I told them all to get fucked.

Arthur would have been proud of me. His speech is so hard to get a word out by the time he told somebody to fuck off, they would be two blocks down the street. Pretentious or pompous, take it anyway you want, but I think telling those fools to get fucked was Arthur doing the talking, not me, I don't like getting hit in the face; the implications of the cart probably kept them from pounding on my skull. I was doing Arthur's Work, I thought, so I merrily strained my aching legs and graphically allowed passersby to share my opinions of them.

(I finally parked the cart in front of 'K House' where Arthur usually leaves it overnight after catching a ride home across the [Willamette River], and wobbled downstairs to the Agora for a cup of coffee and to think about my maniacal odyssey across town.)

A couple of days later (Portland Mayor) Neil Goldschmidt showed news(persons) the difficulties in living out of a wheelchair. That was the day Michael Goldhammer sat in his wheelchair and read a statement Arthur had written for the press. He had put enough pressure on City Hall for them to suggest a planning commission with physically handicapped as members, determining facilities for them in present and future buildings. Arthur's statement thanked them for doing something they should have done fifty years ago, and gently suggested it was only the first small step towards demanding and getting self-determination for the physically handicapped.

That's an expression for you. 'Physically Handicapped'. Solemn, ominous perhaps, but shorn of the anguish and pain and daily guts it takes to live in a society that doesn't see them. An official expression designed to keep them and everybody else from thinking of them as anything but a medical problem.

Who are the physically handicapped? They are people like Arthur Honeyman and Michael Goldhammer who have been crippled in their bodies one way or another through physical birth defects or disease — I grew up before Salk made his vaccine; polio threatened all of us. They are the aged whose bodies have withered. And they are the young who the politicians sent off to get paralyzed or lose their arms and legs in a war.

What Arthur Honeyman and Michael Goldhammer are trying to do essentially comes down to stressing the political power these thousands of people have towards determining their own lives. They are not 'medical problems' living at the charity and expense of society — they are a terrific political force, the potential of which frightens hell out of politicians.

Ugly people, fat people, hunch-backed people, crippled people, Black/Brown/so-called Yellow & Red people, people with pimples, midgets and dwarfs, bearded ladies and sword swallows: Freaks — Evil! The only people I do not fear are those who are like me, except I fear myself and mistrust everybody who is like me — isn't that the strange (psychotic?) dichotomy we live under?

Arthur Honeyman's body shakes with the spasms of my brain, of all our brains, spastic and uncontrolled: his outsides are what all of us are inside. Most of us think we live in our bodies, pursuing bodily pleasures for their own sake. Arthur's body doesn't work so well so he lives consciously where the rest of us live subjectively (if not accidentally). He is never considered in our daily life patterns, so he is faced every minute of every day with emotional and physical obstacles designed to break the will of even the strongest gorilla in the jungle.

"I am tired of the feeling that I am treated like a mascot," Arthur wrote — actually he dictated it to be written — in an open letter recently. "I am tired of being a pillar of institutional respect... My cause is not just to get better facilities for the physically handicapped — My cause is not just to maintain better communication with the physically handicapped, but my cause is also to get rid of an atmosphere of paternalism towards the physically handicapped. That is why I bear my sign saying:

SPASTIC POWER IS AN IRRATIONAL FEELING  
BUT THEN, SO IS LOVE

(Portland Scribe, August 1972)

\*Michael Marsh died in May 1991. (See "Michael Marsh & The Egyptian Mercenary Army," by John Paul Barrett, NCTE, May/June 1994; and "Sardonicus Rising" by Michael McCusker, NCTE, May/June 2001.)