



MICHAEL deWAIDE, FROM 'SAM & HIS CART'

Some CPs are disturbed by spasticity in their eyes, which may receive double vision, reducing the person's sense of balance.

As with all CPs, disturbances like these are caused by misdelivery of the message to the brain through the nerves resulting in an inaccurate perception of the eyes. An example of an athetoid's problem of muscles is when an athetoid reaches for an object — nerve cells misdirect the hands so that the object is not reached or knocked over. Also, in many CPs hearing may be defective. The result is that the CP may appear to be stupid or uninterested.

For centuries the CP was regarded as an idiot because of spasticity, drooling, speech and other convulsive traits. CPs can be paraplegics (which refers to two limbs), quadriplegics (four limbs) or hemiplegics (one side of the body).

Because *athetosis* is the affliction I suffer, I am going to concentrate on it. Also, I believe it to be the most terrible of the various types of cerebral palsy. The reason is this: Many victims of *athetosis* are not able to write or feed themselves, display annoying and unpleasant actions such as facial contortions and drooling and exhibit wormlike movements. This naturally means the CP is not readily accepted by society. Obviously one can see what this would do to the average CP's social standing.

The athetoid can be extremely strong physically and still not be able to attend to the simplest things which the average person takes for granted. I can lift myself up by using an over-head bar so that my feet don't touch the ground, but I cannot hold on to a glass of water — not because I am not strong enough but rather because I am uncoordinated and the glass shakes out of my grasp. The harder I try to do something the more difficult it becomes. I become excited and tremble (which almost everyone does from fear or excitement) to a much greater than normal degree; I spasticate. One may ask, "Why not relax?" Of course I should relax. I would be able to do all sorts of things. I would be able to speak better. But it is difficult for an athetoid to relax. It takes us rigorous and slow training and development of muscular control to relax. This depends partially on the severity of the affliction, partially on individual character (up-bringing, background and environment), and also on medical facilities as well as psychological or psychiatric treatment.

I believe the greatest overall problem which a CP, especially an athetoid, faces is the problem of being socially accepted. One cannot rightfully expect to be accepted on an equal basis by society unless he or she proves equal to it. This is true whether it is blacks, Jews, alcoholics or CPs. On the other hand society must give each the equal chance to prove equal, which it does only reluctantly and slowly. This means minority groups must work twice as hard or more to achieve acceptance. This is extremely difficult for a CP, particularly the athetoid because of the inability to function as well or as fast as the average person. It is also difficult to make friends because of spasticity, drooling, unpleasant facial expressions and speech defects.

Victims of other afflictions such as polio, muscular dystrophy, muscular sclerosis, and so forth, do not always accept CPs to be on their own level. CPs must prove to be equal to them. I first discovered this while attending a school for crippled children. I was shocked and hurt and I don't think I have ever quite recovered from this realization. A roommate at the school coined an interesting but unoriginal phrase, "The only good CP is a dead CP." This in essence expressed the feeling of almost all who did not suffer CP.

Very few CPs marry and very few have much of a home life, if any, after their parents die. It is a problem for the public to take care of those afflicted with CP. For years the problem was taken care of by conveniently tucking CPs out of sight and putting them in a dark corner where they lethargically pass the time. The public is slowly arriving at an awareness that the CP is included in the human race. There are special schools, special homes, special associations for the CP. However, there is a tendency to confine CPs or all cripples into one little social group.

The life expectancy of a CP is considerably less than a average person. This does not mean they die early because of physical degeneration, but rather from psychological attitude. This attitude is primarily from not being accepted in society on an equal basis and not being able to do what the average person can do.

Education is crucial to the survival of CPs as well as all handicapped persons (even more than to non-handicapped). The individual who is both versatile and efficient takes priority in the job market, especially when jobs are scarce. It requires skill to become and remain employed even in the best times. This is especially true now when people everywhere are being laid-off. So-called able-bodied unemployed workers can do hard labor or other physically oriented tasks. Not so with CPs or other handicapped who find it difficult to be employed at any time. Education, doesn't guarantee jobs, but it does help, especially disabled jobseekers. During times of government cutbacks, we "handicaps" have to be resourceful just to stay alive without financial aid from agencies or organizations of some kind, public or private.

I would have never have been employed without a decent education. Luckily I was able to attend college. Both of my degrees (B.S. in History and M.A. in English) have not directly related to any position I've held, but they give me more credibility than no degree. Combined with my real-life experience, my academic education has given me the skills to create every job I've ever had.

Throughout the ages the CP has been treated more as an animal than as a person. In ancient Greece, for instance, CPs were thrown over cliffs to their deaths because of their uselessness — as were all physical cripples. During the Middle Ages they were locked away in dark pits along with the mentally insane. During the Renaissance period artists depicted them as creatures in their works. A carving from ancient Egypt was dug up of a person whose body was deformed in such a manner to indicate he suffered from cerebral palsy.

It has not been until recently that CPs were allowed out into the streets and to intermingle in society. During the late 19th century, for example, CPs were confined to rooms and were more or less a thing nobody talked about. CPs are much better off than they have ever been, and the future looks brighter than the present. The promise that modern technology and medicine might come upon at least a partial cure has become more likely. More than that, the public is becoming more aware and understanding of the problems of cerebral palsy, which means CPs can hope for a more pleasant future.

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## IS SPASTIC POWER AN IRRATIONAL FEELING?

BY ARTHUR HONEYMAN

They no longer throw people like me over a cliff. I should probably find that example of historical progression comforting — but I think it is threatening instead.

I am a spastic. I was born with cerebral palsy. I am a freak. My body shakes like four winds tearing at it from all points of the compass. My speech is tortured almost to being incomprehensible. I drool and vomit almost uncontrollably. I cannot even write without laboriously dictating to someone.

I also cannot eat unless someone feeds me. To go to the bathroom, someone has to take me, put me on the toilet and wait until I am finished. I have to be undressed for bed and dressed the next day for work and school. I am (65) and have to be cared for like a six month old baby.

But my mind is free. I am a scholar, a poet and teacher. I have campaigned twice for the Oregon State Legislature and I have traveled alone or accompanied by friends throughout the United States.

I am a freak and sometimes an embarrassment to others, but not to myself. Living within this shaking body, however fettered it may seem, is to me the most natural way of living because it is the only life I have known.

I do not exist because of society's benevolence. I am not a charity case dependent upon a historical moment of benevolent distraction by the larger society. And I am not alone. Within the greater Portland area there are some 70,000 persons officially classified as "physically handicapped."

These people are the chronic cripples such as myself, born with cerebral palsy or other malfunctioning or missing parts. They are aged whose once strong mobile bodies have withered and decayed to an almost functional paralysis. They are the deaf and blind. They are the victims of accidents and wars, many especially from the profusion of landmines and booby traps used in the war in Southeast Asia which rendered an unbearable proportion of young men without arms or legs, not to mention the great number who lost their sexual organs.

These are the physically handicapped. There are many thousands of us, but somehow we remain functionally and politically invisible.

Let's face it, the "problem" of cripples is not a priority. It is not even a priority to cripples themselves. Cripples are doing alright these days — they're not being thrown off cliffs.

My analysis of the political situation of cripples in Portland and in all major cities starts with the notion that people do not want to talk about it nor want to do anything about it, and when they do something, they want to do it quickly, to get it over with rather than follow it up with new ideas and new forms of action.

Because mobility and easy access to most parts of the city is virtually impossible, urban life for the physically handicapped is almost a nightmare. More than just physically forbidding, it is psychologically debilitating.

The term *physically handicapped* is itself a psychological handicap — it implies that we are just a medical problem with which the larger society has to contend. It makes us feel as if we are not responsible for ourselves but are totally dependent for our survival.

Yet, the fact that there are so many thousands of us in just this metropolitan area alone could be of considerable significance. Together we could have forcible impact on decisions — or the lack of them — that determine our lives. We are potentially visible.

Cripples themselves are reluctant to act because they do not realize what positive things action can do. They feel only the negative aspects; they feel they will lose money from the Division of Vocational Rehabilitation or financial and moral support from charitable organizations and friends.

Cripples have been taught from early childhood to be grateful for what they have and to smile bravely in spite of the hardships, or they are indeed surviving in a benevolent society.

Given the expectations and dependencies with which I was raised, it takes a lot of gall to write something like this which does not show a humble and grateful cripple.

As far as I know, I am the only one who writes about cripples from a political viewpoint. It has been my experience that even so-called political radicals — the "champions of the underdog" — do not write about cripples. Political liberals write about what is being done for cripples, but not about what is not being done. Cripples not only do not write but they don't think I should write; the boat shouldn't be rocked, especially by a spastic.

Part of the problem is that some cripples go inside themselves to find inner religious sources of comfort, thereby ignoring the terrible realities and problems they confront. Having found that solution, they are only perpetuating the problems they so greatly fear.

I am called a cynic because I challenge the spiritual call in order to find and take political action. A spiritualist does not disturb the existing order of things. A spiritualist accepts. Acceptance is what makes people happy.

I am more interested in survival.

A woman told me years ago that I would be better off dead. The statement itself almost scared me to death, but it taught me a valuable lesson. From then on, survival has been my primary interest.

Survival depends upon a multitude of factors — foremost among them is the realization that cripples like myself cannot allow our survival to be wholly dependent upon the good graces of society. We must understand that we are a social and political force and have the power to determine our own lives. We must also make society realize that we are citizens also, that we have as much a vested interest as anyone in the political processes that determine the planning of our cities and the forms of our government.

If society continues to see us with blind eyes, if society continues to regard us as a problem instead of as an integral part of that society, then I predict that politically the cripple has no hope for survival, especially when it comes to the question of emergency life or death conditions which could occur in times of political chaos or intensified fear. Under such conditions, cripples will be more than a social inconvenience, they will be an expendable danger to society and mercifully killed again.

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