

MATRIX OF A SOCIAL SPASTIC

BY ARTHUR HONEYMAN

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 paranatal, 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 paranatal (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. Paranatal 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 uncoiled 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.

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

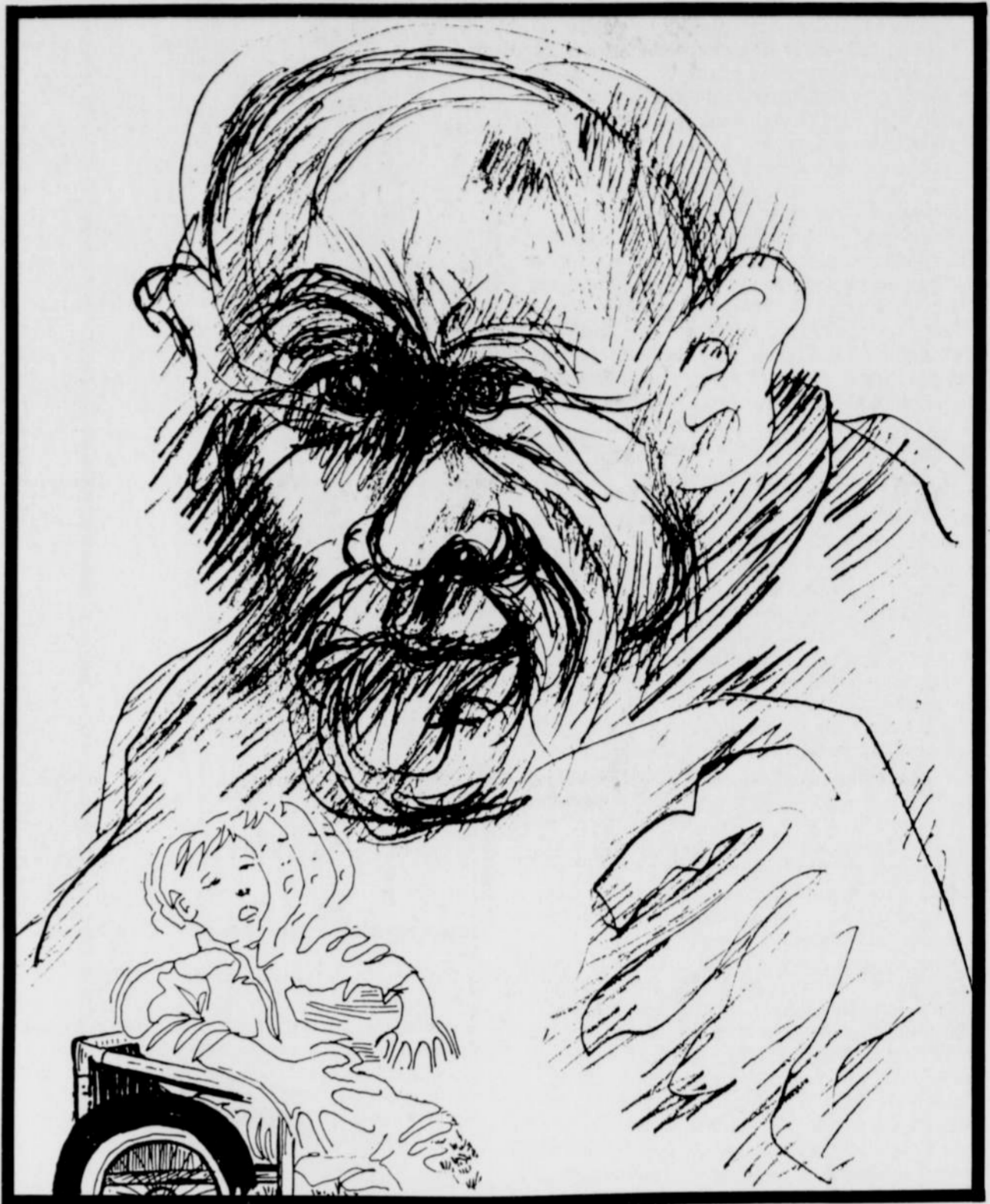
As with all CPs, disturbances like these are caused by misdelivery of the message to the brain through the nerves resulting in an inaccurate perception of the eyes. An example of an athetoid's problem of muscles is when an athetoid reaches for an object — nerve cells misdirect the hands so that the object 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



ARTHUR HONEYMAN YOUNG & OLD BY MICHAEL deWAIDE

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.

Arthur Honeyman is a teacher, poet and writer. He is 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.

Michael deWaide illustrated 'Sam & His Cart'. He lives in Astoria.

CRIPPLES FOREVER

"Only a decadent society will let them live without any ulterior motive."
We're not even good enough for institutions.
Throw us off cliffs. Forget constitutions.
Society can't afford the taxes.
Should be sharpening axes.
Soon you won't need to be frantic or frenetic.
Blond perfection will be automatic, genetic.
"I apologize for my existence."
What's that? Christian resistance?
Now really, I mean realistically,
Survival and cripples. Forget idealistically.
This ain't real.
It's surreal.
But drooling, incoherent shaking s-s-spastic
Writes a poem for the city club, *fantastic! Iconoclastic!*
And Kocher
Crippled little bloker.
Keeps on stoking
Pushing, shoving, screaming, burning, funny little arms, joking.
The one liner:
Kocher is a Shnner.
So we're making demands.
Though we don't deserve to live, expecting reprimands.
Do you realize
How many desperate cries
Sweep the nation
'Cuz there ain't no transportation?
And in your deepest dreams.
No arms, no jobs, just screams.
And the retarded?
Ooops, I drooled, I farted
Now in society (today, yesterday, tomorrow) cripples
Don't make disturbing comment or ripples.
I can tell this by the way you don't stare,
'Tain't fair, I swear, I swear, I swear, to dare.
Did you know there are black cripples, yellow
Cripples, red cripples, white cripples, mellow
Lazy cripples, fat cripples, old cripplles, cruel
Cripples? That's why they go to special school.
Some of us shake. Some crawl. 'Don't do nothin', but accept.
Guess what? I got muscles. I got a bicep. How's that concept?
Tell you what I am. I'm a cotton pickin' rammer.
So's Kocher. Even Goldhammer.

So the truth is across the bridge, on the other side.
The revolution of the cripple is yet to be cried.
It's evolution and you, my friend,
Are helping the freak in its sporting trend.
Each evolutionary freak may be the power of tomorrow.
Power to the cripple. Power to the archetype, the limping hero!

~ARTHUR HONEYMAN (1976)