QUADRIPLEGIA: WHAT DOES IT MEAN?

While a student at The Ohio State University in 1963, Dick Maxwell sustained a spinal cord injury while playing intramural football. As a quadriplegic, he completed his bachelor's degree in business administration. After graduation he worked as a patient services coordinator at the University Hospital complex for several years. He retired as an Assistant Director of Disabilities Services for the University.

In 1970, Dick addressed a national medical meeting in New York and the national convention of his fraternity Phi Delta Theta. The speech was published in the May-June 1971 issue of the Journal of Rehabilitation.

What It Means Personally

Could you answer the question, "What is a quadriplegic?" beyond the oversimplified statement, "He is paralyzed from the neck down."? Basically, it means that once the spinal cord is severed or severely damaged, all nerve control of the body, both sensory and motor, is lost below that point and cannot be repaired. For the quadriplegic, his injury or spinal cord disorder has occurred high on the spinal column and the resulting paralysis affects all four of his body's extremities, hence the prefix "quad," meaning four, and suffix "plegia," meaning paralysis. Fifteen years ago the medical profession was unable to save the lives of patients with high spinal cord injuries; there were just too many complications to overcome. More recently, with the advanced techniques and new procedures of modern medicine the quadriplegic is saved. Through intensive rehabilitation programs, he is then trained to utilize all of his unaffected muscular control above the injured cord level, but the fact remains that he will be paralyzed for the rest of his life.

Physical Dependency

Yes, it means he is paralyzed, but it means much more. It means he is entirely dependent on others for the rest of his life, for every physical activity. He is a mentally independent individual who has lost all of his physical independence. It means that for the rest of his life he will see the world from either a sitting or lying position. He cannot dress himself, wash his face, brush his hair or eliminate his body wastes without someone else's help. It means he cannot hold the hand of someone he loves, because he cannot grasp. And if a loved one holds his hand, he cannot feel her touch. He cannot straighten a magazine if its crooked position on a table bothers him. It means that if he is ill he cannot cough or sneeze because he has no muscular contraction in his chest. When someone extends a hand in greeting, all he can do is look, smile and hope the person will drop his hand. He cannot get over a curb, do his own shopping for a gift or go to the library to study. It means near emotional destruction for himself and his family. It means that if he wants a date, a friend has to look up the number, dial the phone and hold the receiver. When the date is made, someone else has to drive, pick up his date and take her home. He cannot adjust the television, open a newspaper, fill his drinking glass, unwrap a piece
of gum or light a cigarette. It means that if there is a draft, he cannot close the window, and if he is warm, he cannot open it.

In short, and this point cannot be overemphasized too much, the quadriplegic is a thinking individual who has his own needs and desires and who must depend on a faceless "someone else" every minute of the day. That someone else may take the form of a nurse, orderly, parent or friend, but they all have to be asked, and thanked, for every normal activity they perform for him. The feeling of dependence is a constant in his life. It means he cannot afford to alienate anyone within his environment, no matter what type of personality conflict is involved. How frustrating would it be for you if you had to direct the movements of someone else's hands and feet as if they were your own to perform the simplest task?

Emotional Destruction

With time you adjust to the physical disability and accept it as something that cannot change, but the most damaging consequence is the constant emotional destruction resulting from dependence on others. The mind is whole and working, having needs and desires, but they must be fulfilled by other hands. This is possible most of the time, but you cannot put another's arms around someone you love. It means that even simple wants, such as where the trouser crease should be, or how a collar should lay, or how a tie should be tied must be explained again and again. It means that every time you come into contact with someone new, all the explanations that have been repeated a thousand times must be told again. It is a life with a longing, burning desire for independence and individuality, with the horribly real fact that it is constantly impossible.

There is an almost unlimited number of things a quadriplegic cannot do, but he can study, think and communicate. I would hypothesize that, ultimately, the only unique quality man possesses is his mind and what it produces. This means that a quadriplegic can be a functioning and contributing part of the society upon which he depends. There are many tasks that can be performed with the use of the mind and speech and without the use of arms and legs.

Inadequate Facilities

Now arises the question, "Where is the quadriplegic to live?" Before a quadriplegic can be a functioning and contributing part of society he must have an adequate facility and environment in which to live. Financially, it is almost impossible for an individual to live by himself or with his family, and maximum welfare is a meager amount that does not approach the cost of nursing home care. At the present time, a young quadriplegic has two choices. He can either mentally and emotionally vegetate at home, or in an institution that provides adequate care for the aged but certainly not an adequate environment for a young person. If the environment is depressing and desperately unstimulating, it is impossible for a person to grow as an individual or contribute anything to the society of which he is a part. This is the problem the young quadriplegic faces. He has the potential to be a functioning part of his society. But, at the present, there exists no facility that has a positive working, continuing program and environment for the young paralyzed person.
If this type of facility did exist, perhaps when the question was asked, "What is a quadriplegic?" the answer would not be, "He is paralyzed from the neck down.", but rather, "He is a person who is active and very much alive from the shoulders up."

POST SCRIPT:

Creative Living has existed since 1974 thanks to Dick and five other Founders. There are 34 HUD subsidized apartments in two complexes located on the edge of The Ohio State University campus.

As the mission states:

Creative Living exists as a non-profit organization to encourage independent living for adults with severe physical disabilities by providing wheelchair-accessible housing and assistance and by creating an environment for people in which to learn, work, live and contribute to the community.