

Never Say No: Reinventing Life from a Wheelchair

by Theodore Plantinga

Every now and then one hears the phrase "a fate worse than death." Is there such a thing? What would count as "a fate worse than death"? For some people, simply being in a wheelchair. John Hockenberry, a paraplegic who makes very effective use of his wheelchair, tells us that someone once said to him: "I guess you are the first handicapped person I have ever seen up close. Have you ever thought of killing yourself?"

Hockenberry reports this tactless remark in a fascinating memoir entitled *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*. [NOTE 1] In this book he explains the circumstances that led to his loss of mobility back in 1976, when he was a young college student. He then proceeds to tell us about his experiences during rehabilitation and his subsequent professional life as a radio reporter. He even includes some interesting material about the more intimate and private side of life, including sexuality. Hockenberry is anything if not candid.

As for the tactless remark quoted in the previous paragraph, it needs careful consideration because the entire book can be read as an answer to the question Hockenberry was asked. Now, if the possibility of suicide had only been raised with him *once*, it might not merit mention in his book. But it seems that more people had the same thought. He reports: "Long before Kevorkian made a cottage industry out of physician-assisted suicide, some people would talk openly about suicide with me. They would ask if I had thought of killing myself, imagining that if I had considered it, the experience of being in a wheelchair would be more comprehensible to them. ... Many people would make this macabre suggestion to my parents, saying openly that if I found it too difficult to continue my life, they should be ready to accept my wanting to die." [p. 77]

The question "Why go on living?" does not generally arise in the course of day-to-day normal life, but it was clearly an issue that Hockenberry needed to face. His willingness to face it squarely gives his memoir an existential tone and makes it a genuine piece of what Germans like to call "Lebensphilosophie" (philosophy of life).

The challenges Hockenberry faces and discusses are very hard to understand for people who enjoy the normal use of their legs, as I do. One almost hesitates to discuss Hockenberry's ideas in public; yet, to remain silent would amount to disrespect and a form of ostracism. Hockenberry deserves to be read and taken seriously.

In addressing Hockenberry's issues, I am of course running the risk that someone may say to me: "First you should walk a mile in my shoes -- or better, spend a month in my wheelchair." Therefore, at the outset I should say something about my own exposure to the needs of people in wheelchairs. It came first of all during my undergraduate days, when I worked as an orderly in a hospital and dealt with a number of people in wheelchairs, although I did not become intimately acquainted with any of them. Secondly, my father-in-law spent the last fifteen years of his life dependent on a wheelchair. Of course I heard him reflecting on his limitation from time to time. Finally, in March of 1999, my wife suffered a very serious brain injury that left her mentally and physically disabled, and dependent on a wheelchair. Because the injury also impaired her ability to think and to express herself, she has not managed to say much to me about her state. She would not be able to read Hockenberry's book -- to say nothing of writing such a memoir herself. And in her diminished condition, I would not want her to contemplate the agonies which Hockenberry reports. Thus, although I have never had to make use of wheelchairs myself, I am by no means unacquainted with them.

Hockenberry stresses that not all paraplegics are alike. The boundary between the functional sector of the body and the affected sector may vary greatly from person to person. As to himself, he explains: "I have a permanent irreversible spinal-cord injury at the chest level." [p. 28] He explains further: "... relatively few people are paralyzed from the waist down. Everyone has their particular line of separating sensation from numbness. Each line of separation is invisible to the eye." [p. 97]

The wheelchair aspect is only part of the daily challenge. Hockenberry explains: "I use a catheter. Every four hours, every day, for the past fifteen years I have had to insert a tube to empty my bladder." [p. 9] He also faces formidable difficulties in the intestinal area: "Total loss of intestinal control

without warning was my own personal doomsday scenario, the kind of event after which life itself hardly seemed possible." [p. 255] After a very embarrassing episode of intestinal difficulty (bear in mind that because of the lack of sensation in the lower part of his body, Hockenberry would not even *know* what was developing), he steps back philosophically, so to speak, and observes: "All human beings have bodies which define their existence and which can veto the best-laid plans of the mind and soul." [p. 256]

Yet most of the book is somewhat more optimistic. When Hockenberry talks about body and soul, I wait for the introduction of the word "spirit," for he seems to possess what old-fashioned writers would call an "indomitable spirit." Yet the term does not come up. Hockenberry chooses his words carefully.

The word of wisdom he wants to leave with us is best summed up in the following statement: "... my entire existence had become a mission of never saying no to the physical challenges the world presented to a wheelchair." [p. 12] We see the "never say no" attitude reflected especially in choices he makes (including risk-taking) as he goes about his daily work. More cautious souls (such as the undersigned) would not make such choices. But then, those who are free in the use of their legs might not find it necessary to engage in a daily struggle for self-affirmation.

Now, Hockenberry did not invent his philosophy of life all on his own. After his accident on a Pennsylvania freeway he was hospitalized in Philadelphia, and then underwent rehabilitation at the Mary Free Bed Hospital in Grand Rapids, Michigan. The rehab folks taught him a few things about developing an independent spirit. He was not to call attention to his wheelchair. The emphasis on independence also meant that offers of help would be a problem. Hockenberry explains: "In rehab we were taught never to allow people to push our chairs. We were taught to do things ourselves and never ask for help. We were proud crips who were going to play basketball and win races and triumph over our disabilities. Outside rehab, self-reliance was a high-risk proposition. To people raised on telethons, it looked suspiciously like a chip on the shoulder." [p. 33]

Hockenberry demands to be taken seriously. At one point he refers to "wheelchair biceps," the well-known upper-body muscle development that we tend to associate with wheelchair users. On the level of the spirit, one also detects something akin to "wheelchair biceps" in Hockenberry's personal make-up. It takes great inner strength to decide that life can -- and should -- be "reinvented." But a stirring affirmation about "reinventing life" is perhaps the most important passage in the entire book: "From the beginning, disability

taught that life could be reinvented. In fact, such an outlook was required. The physical dimensions of life could be created, like poetry; they were not imposed by some celestial landlord. Life was more than renting some protoplasm to walk around in. It was more than being a winner or a loser. To have invented a way to move about without legs was to invent walking. This was a task reserved for gods, and to perform it was deeply satisfying. None of that was apparent to the people who stared. To them, I was just in a wheelchair. To me, I was inventing a new life. To them, I was getting by in dealing with my predicament. To them, I was standing on a ledge and not jumping off. To me, I was climbing up to get a better view. There is no place to jump off. Whenever I look down, I can see my feet. They're along for the ride. There's no reason to be afraid." [p. 79]

These stirring words by Hockenberry have a distinctly American ring to them. Francis FitzGerald has written: "That individuals could start over again, and if necessary reinvent themselves, was one of the great legends of American life. It was the stuff of self-improvement manuals, generation after generation, and the attempt was a major theme in American literature." [NOTE 2] In Hockenberry's brave prose, one hears echoes of Ralph Waldo Emerson.

Philosophy courses in secular institutions often take up the theme "the meaning of life." Textbooks and anthologies designed for use in such courses usually feature this theme as well. In case the phrase sounds rather vague and amorphous to you, let me indicate that part of its meaning is the very question so tactlessly thrown in Hockenberry's face: "Why don't you just kill yourself and be done with it?" This is a question, according to some, that we must all face, regardless of whether we are classified as disabled or find ourselves dependent on prostheses or aides of some sort for everyday living. If you can't think of an answer to the question, then life has no meaning. In that case you are a coward, because you lack the courage to end it all. But if, on careful reflection, you come up with an answer, you will have established that -- for you, at least -- life *does* have a meaning. A worthwhile exercise, I suppose, for people who often think desperate thoughts.

In Christian colleges, the "meaning of life" theme does not normally play much of a role in philosophy courses. Presupposed in such courses is the grand idea that there is a transcendent purpose to life which is established by God and is known by us only in part. This thought can be a great comfort in a time of adversity. One wonders why this or that must be endured, and then is told that there is a reason for it all, a reason that might not become clear until one enters the life to come.

At this juncture I suppose I could criticize Hockenberry for not posing the basic questions in his life in Christian -- or at least theistic -- terms. In doing so, I would simply be indicating that I disagree with basic elements in his thinking, however much I admire his courage and tenacious spirit. I remain committed to the belief that our destiny is determined in good measure by a Wisdom that far transcends our own. Therefore I also believe that the key to fulfillment in life lies in reconciling ourselves to the transcendent purposes that seem to shape us. The key to prayer is "Thy will be done": we should strive to align our desires and goals with divine purposes. I do not pretend, however, that it is easy to utter such a prayer in times of great adversity and disappointment.

But in taking issue with Hockenberry, I also want to comment on the notion of "reinventing." In practical terms there is certainly something to it. Hockenberry does not want people in situations like his own to quit before they have even started. If they will only open their minds to some new ideas and possibilities, there may be a brighter future for them than they had dared to dream of. His discussion of sexuality (I leave the details to readers of his book) helps us see what sorts of things might yet be dreamed of.

Now, there are purists among us who are inclined to argue, "If God had meant us to do such-and-such, he would have made us with" Arguments of this form are often directed against devices or technological extensions that seem to blur the boundary between man and the things he uses for everyday living. Here we may feel inclined to reflect on the emergence of what Marshall McLuhan called "discarnate man," and then plead for a return to a simpler time.

Yet such arguments are ultimately uncharitable -- perhaps even mean-spirited -- when we consider the limitations which certain medical conditions place on some members of the human community. Surely God intended man to get from place A to place B by using his legs; yet who would begrudge the paraplegic the use of his wheelchair? There is indeed something unnatural about such a device, and one wishes that there was no need for it; yet, the device as such is a good thing, given the circumstances. There are many more prostheses that might seem "unnatural" to the purist but which have a place among us since we wish to enrich the lives lived by people who suffer from this or that disability.

Even so, there is a danger of going too far in this general area. I admit that it is very, very hard to draw the line between the natural (to be applauded) and the unnatural (to be avoided). And I freely grant that we should experiment, especially with an eye to meeting the needs of people with disabilities. Yet as we do these things, we should not conceptualize the situation in terms of "reinventing" what it is to be a human being, as though we might one day leave

the flesh behind altogether and thus become truly "discarnate." Man is not his own maker, and neither does he invent or reinvent himself as he goes along.

Self-knowledge is a rare commodity, and it is difficult to obtain, as Socrates made clear so long ago. We should strive to discover the good for man, but we will succeed only in part. And we can easily be mistaken in this area. What we take to be the good might turn out, after painful experience, to be evil. There is a place for caution, for traditional thinking, when it comes to such matters.

Humanism, however, is inclined to throw such caution to the winds and to invite us to redefine and reinvent ourselves freely. Centuries ago, during the Renaissance era, Pico della Mirandola posed the problem for us in his "Oration on the Dignity of Man," in which he placed the following fascinating words in the mouth of God, who was then addressing our first parents: "Neither a fixed abode nor a form that is thine alone nor any function peculiar to thyself have We given thee, Adam, to the end that according to thy longing and according to thy judgment thou mayest have and possess what abode, what form, and what function thou thyself shalt desire. The nature of all other beings is limited and constrained within the bounds of laws prescribed by Us. Thou, constrained by no limits, in accordance with thine own free will, in whose hand We have placed thee, shalt ordain for thyself the limits of thy nature. ... Thou shalt have the power to degenerate into the lower forms of life, which are brutish. Thou shalt have the power, out of thy soul's judgment, to be reborn into the higher forms, which are divine." [NOTE 3]

It is my firm belief that man is ultimately constrained by limits set in place by *God*. But I also believe that if man *thinks* himself to be essentially unconstrained, he may well degenerate into those "lower forms of life" of which Pico spoke. Many sad events of recent generations provide evidence of such degeneration and brutalization. Not every change is an improvement.

Now, I do not mean, by implication, to point the finger at Hockenberry as paving the way for degeneration. Rather, I believe his memoir should be read as opening up the world and the needs of the paraplegic to people who enjoy the normal use of their legs. But I do take issue with some of the rhetoric he uses as he seeks to inspire people. Hockenberry's "reinvention" is essentially creation, and creation is the prerogative of God alone. **END**

NOTES

[NOTE 1]

New York: Hyperion, 1995; see p. 97.

[NOTE 2]

Cities on a Hill: A Journey Through Contemporary American Cultures (New York: Simon and Schuster, 1986), p. 23.

[NOTE 3]

Quoted from *The Renaissance Philosophy of Man*, ed. Ernst Cassirer, P.O. Kristeller and J.H. Randall, Jr. (Chicago: University of Chicago Press, 1948), pp. 224-5.